# First Steps

Stories on Inclusion in Early Childhood Education

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The success of the inclusive school depends considerably on early identification, assessment and stimulation of the very young child with special educational needs. Early childhood care and education programmes for children aged up to 6 years ought to be developed and/or reoriented to promote physical, intellectual and social development and school readiness. These programmes have a major economic value for the individual, the family and the society in preventing the aggravation of disabling conditions. Programmes at this level should recognize the principle of inclusion and be developed in a comprehensive way by combining pre-school activities and early childhood health care ●

The Salamanca Framework for Action, Article 53

### Preface

The importance of early childhood development for all children, including those with special educational needs, was endorsed in the World Declaration on Education for All (Jomtien, Thailand, 1990) and the Convention on the Rights of the Child (1989). Specifically, the Convention on the Rights of the Child proclaims that 'Children have the right to life and the best possible chance to develop fully' (Article 6), and 'Disabled children must be helped to be as independent as possible and be able to take full and active part in everyday life' (Article 23). Furthermore, the World Conference on Special Needs Education (Salamanca, Spain, 1994) highlights early education as a priority area.

This early stage in life is not only crucial to a child's future development—it can also be a time for children to discover differences in a positive light, learning to live, to play and to learn together. These 'first steps' are extremely important in facilitating inclusion throughout schooling.

UNESCO invited practitioners to share their experiences in the area of inclusive early childhood education. The series of case studies presented here are included because they

- 1) recognize the value of early detection and intervention,
- 2) integrate children with special needs in regular care and education, and
- 3) have an early childhood component.

While some describe the content and application of inclusive early childhood programmes, others focus more on legislation, political context and the history of the effort, with less information on field application.



The programmes can be compared within a variety of dimensions and placed on several continua. For example, they vary in terms of the roles and responsibilities of different sectors, i.e. education, health and social services. This leads to quite different service models. The case studies can also be classified in terms of the degree of government, non-governmental organization and community involvement. While some are government programmes, others are primarily developed by non-governmental organizations, although sometimes in partnership with the government. Some programmes rely heavily on the community, although a non-governmental organization may be the facilitator of the process.

A related dimension is the involvement of parents. Their role can be seen on a continuum, from 'needing to be taught', to 'needing support' to the other end of the continuum where the responsibility is placed almost entirely on the parents to develop and deliver services.

Many of these stories illustrate important 'first steps' towards inclusive early childhood education. As the practitioners and their partners move forward, they are facing challenges and constraints, learning important lessons along the way. We hope that their experiences may contribute something of value to others who are working towards making inclusive education a reality.

<sup>\*</sup> This compilation of case studies will serve as a reference document for the International Consultation on Early Childhood Education and Special Educational Needs, organized by UNESCO in collaboration with UNICEF (Paris, September 1997).

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# The ethnic child care family and community services co-operative: inclusive early childhood education programmes in New South Wales, Australia

By VIVI GERMANOS-KOUTSOUNADIS and MENI TSAMBOUNIARIS

This paper outlines the historical, political and policy context for inclusive early child care in Australia. It provides demographic information about the type of provision and its take-up by various groups and then goes on to outline two specific initiatives run by the Ethnic Child Care Family and Community Services Co-operative (Ltd) in New South Wales. The Ethnic Child Care Family and Community Services Co-operative is a State-wide umbrella organisation, or "state peak". It is based in the State of New South Wales and is a non-governmental community-based organisation with a membership of 45 ethnic and generalist organisations operating children's, welfare, social, health and other services. It is funded by the Federal and State governments of Australia, to help ethnic children and families to obtain equitable access to children's and disability services. The Co-operative's philosophy is driven by its commitment to multiculturalism in children's and disability services.

'assists families with dependent children to participate in the work force and the general community by ensuring that child care is affordable for low and middle income families, and by improving the supply and quality of child care. The provision of such services is an important contribution to the Government's labour market and social justice objectives.'

The New South Wales (NSW) state government is also involved in children's services. It is responsible for the setting of, and monitoring of compliance with regulations for the operation of services. Services are subsidised to facilitate the employment of qualified staff. In agreement with the Commonwealth, the government contributes towards the capital costs and funds the out-of-school-hours care, vacation care and mobile services for remote and isolated areas. It also provides funding for special needs groups to be integrated into pre-schools and this is being extended to include funding for integration into other types of children's services.

#### BACKGROUND INFORMATION

#### 1. Childcare services in Australia

The Department of Health and Family Services (was Department of Human Services and Health) is responsible for the Children's Services Programme of the Commonwealth government which:

Census of child care services in Australia

A census of child care services is conducted regularly by the Commonwealth government. The 1993 census of child care services provided information about four types of children's day care services funded under the Children's Services Programme: community-based long day care centres; private long day care centres receiving childcare assistance; employer-sponsored and non-profit centres receiving childcare assistance; and family day care schemes.

Questionnaires requesting information about the attendance of children for one week in August were sent to 2,908 of these services and responses were received from 2,807 services, a response rate of 96.5%.

The breakdown of services responding was as follows:

| Service type                          | Percentage of responses |  |
|---------------------------------------|-------------------------|--|
| Private long day care centres         | 45%                     |  |
| Community-based long day care centres | 37%                     |  |
| Family day care schemes               | 11%                     |  |
| Employer non-profit centres           | 7%                      |  |

#### Attendance figures for 265,300 children were:

| Service type                                                 | Percentage<br>of children |
|--------------------------------------------------------------|---------------------------|
| Private long day care centres receiving childcare assistance | 37%                       |
| In family day care schemes                                   | 30%                       |
| Community-based long day care centres                        | 29%                       |
| Employer-sponsored and non-profit centres                    | 4%                        |

The average number of hours of operation per day of the four types of service was 10 hours.

The survey showed that 84% of children below school age (0-4 years) use Commonwealth-funded long day care child care services. Of the children under 3 attending Long Day Care Centres, 44% were cared for in Employer Sponsored Non-Profit Centres, 39% in Community Based Long Day Care Centres and 29% in Family Day Care Centres.

The high priority groups for funded child care were working parents, those studying or training for work or seeking employment and sole parents, whose children constituted 22% of all children in the Census. Other priority groups were parents of children with disability, Aboriginal and Torres Strait Islander (ATSI) families, children from a non-English speaking background (NESB), and children referred because of risk of serious abuse or neglect.

#### Children with Special Needs

The proportion of Children with Disabilities in the total population of 0-4 years old, in Australia is 4.4% (ABS Survey of Disability and Ageing, 1993). Of these children:

- 3.2% attend Community Based Long Day Care Centres
- 1.8% attend Family Day Care Schemes
- 1.8% attend Employer Sponsored Non-Profit Centres
- 1.6% attend Private Long Day Care Centres

#### Staffing

Eighteen per cent of responding services were supported by supplementary workers during the survey week. The SUPS (supplementary workers programme) grants are provided to promote access, equity and quality care for special groups of children. More of the community-based long day care centres (28%) were assisted by SUPS workers than any other service. The average hours per child assisted by SUPS in NSW was 2.3 hours per week for children with disabilities, 1.24 for ATSI, 1.09 for NESB and 1.3 for other children.

Of the children assisted by SUPS in NSW, 14% were children with disabilities, 14% ATSI, 61% NESB and 11% other. For Australia as a whole, the breakdown is: children with disabilities 17%, ATSI 14%, NESB 57% and other 11%.

Australia wide, 16% of staff in community-based long day care centres are from a non-English speaking background, 9% of staff in private centres, 13% in employer and non-profit long day care centres, and 9% in family day care. Just 1% of staff are Aboriginal and Torres Strait Islander people and most of these are employed in multifunctional Aboriginal child care centres. For NSW, the proportion of staff from NESB employed in the four types of services is 18% and for ATSI it is 1%.

#### Children in New South Wales

The state of New South Wales, where the inclusive early childhood education programmes are conducted by the Co-operative, has a total of 1,046 services with 85,745 children attending and 12,146 paid staff. The distribution of children in long day care for work-related versus non work-related reasons is:

| - sole parent, work-related                     | 14% |
|-------------------------------------------------|-----|
| - both parents, work-related                    | 64% |
| - sole parent, not working                      | 5%  |
| two parents or one of both parents, not working | 17% |

Of the children attending services in NSW, the proportion of children with special needs in each is as shown below.

## 2. Policy/political context regarding children with special needs

The 1972 Child Care Act

Back in 1972, the Australian Federal Government's social policy included the aim of providing access to child care for all parents who needed it. The Government wished to assist women to join the work force, and as the private sector was unable to meet the child care needs of families, it introduced the Child Care Act (1972). This Act established the Children's Services Programme and the Federal Government's involvement in child care. The Act was based on the central principle of community-based child care, where parents participated in the establishment, management and operation of services. The Federal Government provided capital funding and staff salary subsidies to child care centres which were then able to employ qualified staff to provide quality care and childcare assistance for low and middle income families.

#### Multiculturalism

Since World War II, Australia has provided a home to 4.5 million people who migrated from some 160 countries of the world, speak 90 languages and practise 80 religions. One in every five Australians was born overseas. Fifty percent of those who were

born overseas came from a country where English is not their first language. Together with their Australian born children, people from a non-English speaking background (NESB) constitute 25% of the Australian population. Australia has one of the most culturally, linguistically and ethnically diverse societies in the world

To meet the challenges of a diverse population, the Australian government introduced its policies on Multiculturalism at the beginning of 1980, which acknowledged the diverse multicultural nature of Australian society and the importance of maintaining and promoting this cultural and linguistic resource. However, the mainstream service providers failed to reflect or meet the needs of migrants. Their services were not equally accessible to migrants and the other 'special needs groups', namely people from a non-English speaking or Aboriginal and Torres Strait Islander background, those with disabilities and those who lived in remote and isolated areas.

In 1986, to facilitate equality and equal access to services for all Australians, the Federal Government introduced its Access and Equity policy as part of its overall policy of Multiculturalism. The policy required all government departments and agencies to produce three-year Access and Equity strategy plans which included corporate goals, management and budgeting statements and performance indicators. The Office of Multicultural Affairs was established to assist the departments in developing these plans, and to monitor and co-ordinate the implementation of the strategy.

#### Disability

Also in 1986, the Disabilities Services Act was introduced and Objective 5 of the Act states:

'Programmes and services should be designed and administered so as to meet the needs of people with disabilities who experience a "double disadvantage" as a result of their sex, ethnic origin, or Aboriginality.'

|                               | Percentage of children attending with special needs |                        |         |      |      |
|-------------------------------|-----------------------------------------------------|------------------------|---------|------|------|
| Service type                  | Disability                                          | Parent with disability | At risk | NESB | ATSI |
| Community-based long day care | 4%                                                  | 1%                     | 1%      | 19%  | 1%   |
| Private long day care         | 2%                                                  | 1%                     | 1%      | 15%  | 1%   |
| Family day care               | 2%                                                  | 0                      | 1%      | 7%   | 1%   |
| Employer/non-profit centres   | 2%                                                  | 0                      | 0       | 20%  | 2%   |



The needs of children with disabilities from 0-5 years were to be considered within the children's services programme. Funding was allocated through the Special Services Programme for programmes like the Casual Ethnic Workers Pool (CEWP) and SUPS to integrate disabled children into these services.

#### A National Agenda

In 1989, the National Agenda for Multicultural Australia was launched which expanded and further strengthened Access and Equity as it included all people of Australia, including the Aboriginal and Torres Strait Islanders, who may face barriers relating to their race, culture, religion, language, gender and disability.

Mr. Sandy Hallway, Acting Secretary to the Department of the Prime Minister and Cabinet, states in his paper 'Multiculturalism as Public Administration: Myths, Challenges and Opportunities', that the National Agenda for Multicultural Australia, clearly defines Multiculturalism as a public policy based on three fundamental principles:

- i) cultural identity the right of all Australians to express their cultural heritage
- ii) social justice the right of all Australians to receive equal treatment and not suffer because of race, religion, language or gender.
- iii) economic efficiency the effective use of the skills and talents of all Australians, regardless of background.

Under the policy of Multiculturalism, the Children's Services Programme of the Federal Government, which was run by the Department of Human Services and Health (now called Health and Family Services), responded to the needs of children and families with special needs, whose take-up of children's services was proportionately lower than that of the rest of the population. In order to facilitate access for these groups to Federal Government funded children's services, and as part of its three-year planning to implement Access and Equity, the Department allocated funding to community groups to set up services to meet the special needs of these groups of children and families.

#### These services were:

- Ethnic Child Care Development Units in five states of Australia, the first one being in New South Wales, as part of the Ethnic Child Care Family and Community Services Co-operative
- The Casual Ethnic Workers Pool (General and Disability)
- The Support Workers Programme (SUPS) for NESB, ATSI and Disability
- Multicultural Child Care/Resource Units
- The Ethnic Children's Services Workers.

The government funds Aboriginal organisations and people to operate their own child care services as part of its policy to facilitate self-determination. These special services provide information, referral, advice, consultancy, advocacy and resources for multicultural

programming. They also raise awareness among children's services staff about the cultural/linguistic/disability and other needs of children and parents. They also assist staff in providing a more relevant and appropriate service for the benefit of the children and facilitate integration/inclusion of the needs of these children as an integral part of service delivery.

Multiculturalism has been further reinforced by the United Nation's Convention on the Rights of the Child, to which Australia is a signatory. Article 30 guarantees certain basic cultural, linguistic and religious rights to ethnic minorities, indigenous and diverse groups, and the programmes mentioned above are an attempt to implement this article. Article 23 of the Convention on the rights of children with disabilities ensures that their needs are considered in government policies and in the allocation of resources in children's services and early childhood education to facilitate their integration/ inclusion into mainstream service delivery.

# 3. Current situation of children/families of children with special needs

As the numerical data provided above show, children with special needs do have access to early childhood services at pre-school level and provision is also made by the education department for those who are over five years old. Attempts are being made to integrate children with disabilities into mainstream education, but owing to a lack of resources and support services, and difficulties with physical access, it is often not possible and these children are still being placed in special schools.

The New South Wales State Department of Community Services provides funding to pre-schools to provide specialist support for children with special needs (SN). Funds are also allocated through the Home and Community Care Programme (HACC) for respite care for people with disabilities, including children. This programme is jointly funded by the Commonwealth and state government. In addition, Commonwealth respite carers funding provides for respite care for children with disabilities. There are also Early Intervention teams which offer support, the SUPS Programme which is outlined in this paper and statefunded community services which provide assistance and support to children with disabilities.

The Disability Services Act (1986, see above) and Disability Discrimination Act (1992) have been instrumental in creating an awareness at both service provider and community level of the rights of people/children with disabilities. People with disabilities have had new opportunities to speak up about their

rights and to demand to be treated as equal citizens with equal rights. Some progress has been made as a result of government initiatives; people with disabilities and their families and carers have organised themselves and set up advocacy and other specialist organisations which they manage and operate by themselves. Their visibility and participation in all areas of life has helped to break down barriers, negative attitudes and misrepresentations of people with disabilities.

#### PROBLEMS AND MAJOR ISSUES FOR FAMILIES WITH CHILDREN WITH SPECIAL NEEDS

#### 1. Problems

- Parents from a non-English speaking background (NESB) do not have adequate access to translated information about services to meet their special needs.
- NESB pre-school children are forced to discard their home language as there are no bilingual programmes and facilities for home language maintenance. This leads to children losing their culture and identity with their parents and ethnic community. This often manifests itself as cross-cultural conflict between children and their parents in later years.
- For NESB children, not maintaining their home language affects their interpersonal relationships, their bonding with their parents and the deeper emotional and psychological aspects of communication and understanding between them and their parents. In cases where parents cannot speak English and the children cannot speak the home language, there is no communication between them and misunderstandings result which sometimes lead to family problems and disintegration of the family.
- There is resistance from some parents and education authorities to including children with disabilities in mainstream schools.
- The equipment and physical access for children with disabilities in pre-schools is inadequate and prevents those with high support needs from being integrated in the centres.
- NESB and ATSI parents face difficulties in having their child rearing/caring practices accommodated in the pre-schools, as staff are often not sensitive to these needs; these issues are not covered in their training.
- States do not have inclusive education policies to

- enable children with disabilities to access the school system as a matter of course.
- Lack of access to transport for parents who have children with disabilities affects their ability to participate in programmes.
- The means testing of benefits for families with children with disabilities often precludes them from accessing services.
- Services are often not sensitive to cultural/linguistic/ethnic community needs and therefore NESB and ATSI families cannot gain equitable access to the services which would help them gain independence and become self-sufficient.
- Families with children with disabilities are isolated because of a lack of support. Families from an NESB are even more isolated because of language and cultural barriers.
- The cost of caring for children with disabilities is high, especially for those on low and middle incomes, those who live in poverty, or are NESB and ATSI families.
- The needs of children with disabilities together with NESB and ATSI are often marginalised and are not an integral part of the mainstream policies and service delivery.
- For ATSI children who have lost their culture and language as a result of the assimilation policies, it is important that they have the opportunity within their communities to relearn their culture, to regain their identity, the spiritual beliefs of their ancestors, to have their land back for self-determination and to be accepted as the indigenous Australian.
- People from NESB, ATSI people and, indeed, the
  general community, lack an understanding of the
  different types of disability and this often creates
  barriers to their acceptance of families with children
  with disabilities. There is a need for educational
  programmes at the local community, service delivery
  and government policy and decision-making levels
  to create an awareness and foster interaction
  and understanding between these groups and the
  families.

# 2. Some strategies for overcoming the problems

- There is a need for support groups for parents from particular NESB communities to enable them to talk about their needs with other parents and to ensure that the disability issue is on the agenda of their community organisations. Communities can be educated through the parents.
- Ethnic radio and TV, together with other ethnic media, are important tools with which to reach isolated NESB families with children with disabilities who are too ashamed to come forward.
- Ethnic welfare, health and educational workers are

- important links in reaching families with children with disabilities as they are the first contact point for the families who experience problems. These workers can also disseminate relevant information to these families and often act as mediators between them and the mainstream services.
- Ethnic and disability organisations play a role in lobbying on a state and Commonwealth level for the needs of the children with special needs and their families. These organisations can involve parents in taking up the issues with both the government and non-governmental sectors to ensure that their needs are considered in policy and decision-making and the allocation of resources.
- The unofficial networks in the local community, such as the priest, the local shopkeeper, the social/sporting/recreation clubs, an influential community leader, an interpreter, an ethnic school teacher, an ethnic organisation, an elder of a particular community, etc., are all important in helping to reach families and children with special needs.
- All groups need to lobby the Commonwealth Government to implement at the Commonwealth and state levels, the UN Convention on the Rights of the Child, the Articles of which include safeguarding the needs of children with special needs.
- The use of advocates whether they are family members, volunteers, friends or paid staff, is key in empowering families with children with disabilities to become advocates for their children.
- The provision of carers/volunteers from particular ethnic backgrounds to liaise with NESB and other families with children with disabilities, and to become their mentors, is a cost-effective way of providing support.
- It is important to provide access for families to various ethnic and other community activities which are offered by community organisations as part of their service delivery.
- Regular consultations with the families are an important way of obtaining information on gaps in service delivery and unmet needs. These consultations can be carried out using focus groups with facilitators who are bilingual for NESB families or Aboriginal for ATSI families.
- Programme which assists mainstream services to become more accessible to NESB people and those with disabilities. An ethnic access officer is placed with a service for two days per week for six months and, together with the staff and management of the service, reviews the structure of the organisation, its policies, procedures and practices. Ethnic communities in the area where the service is based are informed about the service, a profile of the population in the area is drawn up and a plan of action for implementing changes to enable more NESB people to access the service is written. Training is provided

to the staff and management on cross-cultural issues, the use of interpreters, Access and Equity policies and how to reach NESB people in the community. This model has been successful with a number of Home and Community Care Services.

 Other cost-effective programmes include the Casual Ethnic Workers Pool and the SUPS Programme, which are described in detail below.

It is imperative for the government to provide resources; the needs of special needs groups are often extensive and costly and cannot be met by voluntary effort alone. Most importantly, children with special needs, and their families, according to the various Acts and Conventions, have a right like all other people to have quality services which are relevant to them and meet their individual needs.

#### PROGRAMME DESIGN AND IMPLEMENTATION: CASUAL ETHNIC WORKERS POOL (GENERAL AND DISABILITY)

#### 1. Project description

The Casual Ethnic Workers Pool (General and Disability) – CEWP – is sponsored by the Ethnic Child Care, Family and Community Services Co-operative Ltd., and funded by the Commonwealth Department of Health and Family Services.

The aim of the CEWP programme is to facilitate the provision of culturally, linguistically and developmentally appropriate children's services to enable families and children with special needs to have equal access to services which are appropriate to their needs. This is achieved through the placement of casual ethnic workers with the children's services.

The CEWP (General and Disability) offers specialised training programmes for men and women to work with children with additional needs (including children from NESB and children with disabilities). The Ethnic Child Care, Family and Community Services Co-operative offers casual employment, through the CEWP, to those who have successfully completed the training programme.

Children's services (including long day care centres, family day care schemes, out of school hours care programmes, occasional child care centres and playgroups) are eligible to apply to have a casual ethnic

worker to be placed in their service to support them, free of charge, on a casual basis. Requests are placed on a waiting list and are followed up as soon as possible.

#### 2. Staffing

The Programme is staffed as follows:

- full-time CEWP Manager
- full-time project officer/part-time project officer
- full-time clerical/payroll officer
- part-time clerical support worker
- approximately one hundred and twenty bilingual/bicultural ethnic workers.

The ethnic workers aim to facilitate the provision of culturally, linguistically and developmentally appropriate child care for all Australian children.

Allocation of casual ethnic workers to a service depends on various factors, including:

- · demand and availability of a particular language
- specific needs of a child with a disability or disabilities
- number of requests from children's services, in relation to the quarterly quota or allocations
- cross-matching of language requested and geographical areas involved in allocating worker to centre
- the availability of hours/funds for allocations.

Casual ethnic workers undertake a range of duties and are required to:

- assist in the development and implementation of multicultural and special needs programmes which have a multicultural/special needs focus
- present activities to staff, children and parents of the centre where they are working
- promote an awareness of diversity
- assist with the integration and inclusion of children from an NESB and children with disabilities from an NESB, into children's services, by providing one-to-one, hands on support
- encourage and facilitate parental involvement in the activities of children's services
- provide information and support, and refer parents to other relevant services – for example, in relation to the assessment of a child with a disability or disabilities
- consult on the development of individualised educational programmes with:
  - parents
  - child care services
  - other relevant health professionals
  - SUPS programmes
  - Project Officer(s) of the Ethnic Child Care Development Unit

- the Ethnic People with Disabilities Programme<sup>1</sup>
  the CEWP Manager.
- encourage, support, maintain and assist with a child's home language
- provide language assistance for children and families of an NESB, to facilitate better communication between children and families.

#### Staff training programmes

The CEWP offers a specialised training programme on working with children with additional needs (NESB and disability). Participation in the general CEWP course is a pre-requisite for entry into the disability course. A complete training programme (General and Disability) is offered over a period of 22 weeks, free of charge to participants.

The CEWP (General and Disability) training covers a range of areas, including:

- the role of the Ethnic Child Care, Family and Community Services Co-operative
- the role of the casual ethnic worker
- the multicultural perspective in early childhood
- multicultural programming
- planning and programming for children with special needs
- the integration and inclusion of children with special needs into children's services
- child development
- · cultural awareness
- · disability awareness
- types of disability
- disability in a cultural context the double disadvantage
- child-rearing practices
- bilingualism in early childhood and the importance of home language maintenance
- the aboriginal perspective in early childhood.

The CEWP (General and Disability) training programme is currently seeking accreditation with the Vocational Education Training Authority Board.

# 3. Mechanisms of early identification of children with special needs

By the time the casual ethnic worker becomes involved with a child with special needs, some sort of early identification has already taken place, as causal ethnic workers are placed in centres on request.

<sup>1</sup> A programme sponsored by the Ethnic Child Care Family and Community Services Co-operative

Early identification of children with special needs can occur through:

- assessments by professionals
- observations milestones in children's development
- developmental checklists undertaken by children's services staff
- consultations with parents and other health professionals, including early intervention services, speech pathologists, psychologists, physiotherapists.

#### 4. Partnerships and liaison

Specialist support services/referral services

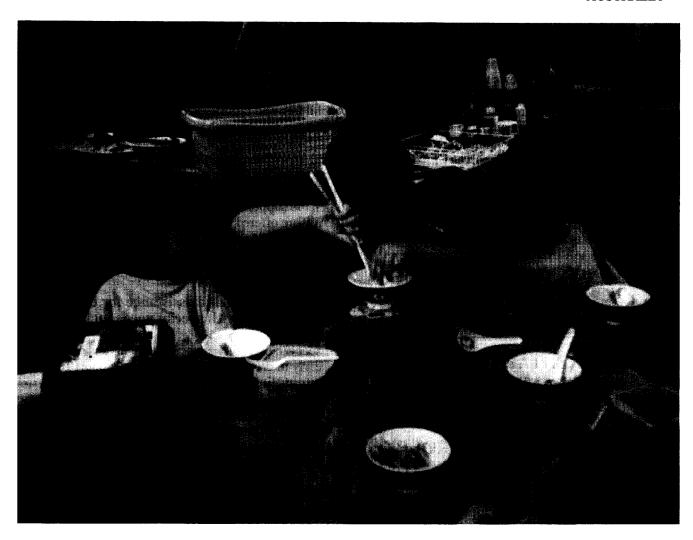
The CEWP programme links with a wide range of support and referral services, including:

- SUPS programmes and workers (disability and ethnic)
- migrant resource centres
- · multicultural resource centres
- specialist ethnic workers and ethnic welfare agencies
- interpreter and translation services
- ethnic media
- early intervention teams (state-wide)
- specific disability agencies/associations for information, support, resources, assessments, early intervention services, parent support groups
- community health centres
- community resource teams for developmental disability, offering school and home-based therapy, social work, community nurse support, paediatric consultations, assessment, information and referral service
- ethnic disability support programmes, sponsored by the Ethnic Child Care, Family and Community Services Co-operative.

#### Partnership with parents/community

Parents play a significant role in the success of the CEWP programme. In many instances, parents encourage centres to apply for casual ethnic workers to work with their children. Parents also provide feedback to workers and CEWP staff on the progress of their child and the effectiveness of the CEWP programme. Parents are usually instrumental in having a placement extended.

Casual ethnic workers work closely with parents, by encouraging and facilitating parental involvement in the activities of the child care centre. Parents are encouraged to extend special needs, multicultural and bilingual programmes developed for their child(ren) to the home environment.



Casual ethnic workers also provide language assistance for children and families of an NESB in order to facilitate better communication between the centre and families.

#### Outreach Work

Outreach work takes the CEWP programme to the community. Of particular importance is the promotion of the CEWP in the ethnic communities. A range of promotional tools is used, including parent information workshops which are held in community languages, ethnic print media and ethnic radio. The outreach work creates an awareness about the programme amongst the ethnic communities and encourages them to access the service. This, in turn, encourages NESB people with experience and/or qualifications in early childhood to apply to become casual ethnic workers.

CEWP staff also make presentations to ethnic, disability and generalist children's services committees to raise awareness, promote the CEWP and recruit potential casual ethnic workers.

Further outreach and community development work is undertaken with the Co-operative's member organisations and ethnic and disability networks. Training is provided to children's services, disability and NESB communities on disability and cultural awareness, through CEWP and the Ethnic Child Care, Family and Community Services Co-operative Training Programmes.

#### 5. Monitoring mechanisms

Annual workplans are produced together with action plans, and both individual and organisational progress are regularly assessed against these.

Casual ethnic workers and CEWP staff are supported and supervised by the CEWP Manager. Their work is evaluated by centres at the end of each placement using evaluation forms. Written feedback is also provided by parents. Centres, staff and parents provide feedback to the CEWP Manager on the success and effectiveness of the programme as it progresses. This is normally done through meetings between the relevant parties.

The CEWP Project Officer offers support and resources to CEWP workers while they are on placement, using the Multicultural and Special Needs Resource Van. The Project Officer also follows up any issues or problems arising during a placement. All programmes run by the Ethnic Child Care, Family and Community Services Co-operative are accountable to the Executive Director and the Programmes Manager, who also supervise and offer support to CEWP staff. The Board of Directors meets monthly and the Programmes Manager and Executive Director report on the progress of the Co-operative's programmes at these meetings. The funding body receives annual programme reports and reviews and the Annual Report includes self-evaluation by the programme staff.

#### SUPPLEMENTARY WORKERS PROGRAMME (SUPS): BANKSTOWN EARLY INTEGRATION AND NETWORKING GROUP

This section describes how the Supplementary Workers Programme (SUPS) works in the Bankstown area, Bankstown is a suburb of The Bankstown Local Government Area in the State of New South Wales. The programme is delivered by the Bankstown Early Integration and Networking Group.

#### 1. The Bankstown area

The local government area of Bankstown has a population of approximately 154,000 of which 32,371 are children aged 0-14 years, representing 21% of the total population. Of these children, 12,863 are aged 0-5 years old (8.4%) and 6,621 are 0-2 years of age (4.3%).

(City of Bankstown Community Profile 1994. Source: Australian Bureau of Statistics, 1991).

There are 51 private long day care centres compared to just seven community based long day care services. (Commonwealth Department of Health and Family Services, NSW office 1994, updated 1996.)

According to data gathered by the Bankstown Early Integration and Networking Group (September, 1996), approximately 4.5% of children accessing children's services in the Bankstown local government area have a disability. Furthermore, approximately 30% of children and families accessing children's services are from a non-English speaking background.

Local experience has indicated that most children's services are available and accessible to children/families of children with special needs, particularly when the support of services such as SUPS and the CEWP are offered. Furthermore, there are specialist early childhood services for children with special needs, focussing on early intervention and support.

# 2. Other support and assistance for children and families with special needs includes:

- specific disability agencies/associations offering early intervention services, parent support groups, information, newsletters, support and resources, and parent/community education programmes
- community health centres, offering assessment services and early childhood nursing staff
- community resource team for developmental disability, providing physiotherapy, occupational and speech therapy, social work, community nurse support, paediatric consultation, psychological assessment, information and referral service
- Early Intervention Association: an association of parents and professionals involved in early childhood intervention, support, policy development and lobbying
- ethnic disability support programmes, such as the ethnic people with disabilities programme
- Casual Ethnic Workers Pool (CEWP).

Additional support is available for children and families from a non-English speaking background, including:

- interpreter services, including telephone interpreter services
- translations of relevant early childhood/children's services and disability material
- specialist ethnic workers, supporting and resourcing NESB communities
- migrant resource centres, offering services for NESB communities
- ethno-sponsored welfare agencies
- ethno-sponsored children's services.

#### **AUSTRALIA**

# PROGRAMME DESIGN AND IMPLEMENTATION

#### 1. Project description

The Bankstown Early Integration and Networking Group's programme is funded by the Commonwealth Department of Health and Family Services and sponsored by the Bankstown Community Resources Group.

The Bankstown Early Integration and Networking Group (BEING) is a team of developmental and multicultural educators, who assist children's services in Bankstown by providing information, resources, support, newsletters, referrals and training on issues relating to working with children with disabilities and multicultural aspects in child care.

BEING works with centre staff, parents and other professionals to promote multicultural and special needs programming for all children, particularly children from all NESB, and children with disabilities. Multicultural and developmental educators can assist children's services in the local government area by:

- providing an advisory/consultancy role on programming and caring for children with additional needs
- assisting children's services staff with the development and implementation of ongoing multicultural and special needs programmes which reflect the needs of all children and encourage integration
- training and empowering staff to integrate children with disabilities and children from an NESB into their services
- providing and disseminating information and resources on disability, the integration of children with additional needs, multicultural programming, etc.
- demonstrating appropriate education/care practices for individual children with disabilities and children from an NESB, to children's services staff and parents.

#### 2. Staffing

The programme staff are:

- a part-time co-ordinator
- a full-time disability worker
- two part-time ethnic workers
- a part-time ethnic and disability worker who assists children from a non-English speaking background, children from Aboriginal and Torres Strait Islander

backgrounds and children with disabilities, to gain access to and become integrated into Commonwealth-funded children's services in the Bankstown local government area.

#### Staff training programmes

The SUPS workers programme receives funding from the Commonwealth Department of Health and Family Services to conduct annual training for its workers. Training is offered in various forms including:

- block training one week of keynote speakers and workshops. All SUPS disciplines (ethnic, aboriginal and disability) come together to discuss common areas and receive training across the board.
- individualised worker training-workers are trained on individual areas of need in relation to their role. Costs are covered by the employer.
- practical "hands on" experience under the support of a more experience SUPS worker.

#### 3. Monitoring mechanisms

Arrangements for project monitoring include:

- evaluation by the co-ordinator of the programme
- evaluation by the organisational management committee
- six-monthly programme reports/review to funding body
- annual workplans, yearly evaluations and plans of action
- annual report/self evaluation
- · periodic assessments against workplans.

#### 4. Partnerships and liaison

As with the CEWP programme, links are made with many other specialist, support and referral services. Similarly, partnerships with parents and the wider community are important; they are involved in the SUPS programme on various different levels. Some parents request the support of developmental educators to work with their child(ren) in child care.

Parents are encouraged to become involved in the operation of the centre at Management Committee level and in the programming for the centre and their child. Parents are also encouraged to extend special needs programmes developed for their child(ren) to the home environment.

Outreach work is also important. SUPS workers are involved in community development activities. They act as facilitators in the local area, developing resources and services to assist children's services

and promote the concepts of multiculturalism and special needs. The SUPS workers create networks and assist in team liaison between children's services staff, parents, the community and other agencies (ethnic and disability) that may be involved with the child and his or her family.

The development of strategies for attracting potential users of children's services from NESB and families with children with special needs is considered crucial in improving access, as are the community education programmes on children's and disability services.

#### 5. Problems and major issues

In addition to the obvious need for adequate and on-going funding of the SUPS programme, there are a number of factors affecting its impact. The following are key to ensuring that the programme is effective:

- the role of workers should involve providing community development, advocacy, resourcing and support, complemented by 'hands on' support. In recent years, the focus of SUPS has moved away from the 'hands on' role, towards the trainer/facilitator role. That is, it has focussed primarily on the training and empowering of children's services staff to enable them to work with children with special needs. This approach cannot work by itself: children with special needs and children from an NEBS need support at a 'hands-on' level.
- assistance to child care centre staff should be ongoing and intensive. Staff need advice, support and resources to enable them to develop and implement multicultural and special needs programmes. Approaches to this should include targeting all staff members, attending staff meetings, providing

- information sessions to staff, and demonstrating appropriate activities/methods. This is a very effective strategy in assisting with the integration and inclusion of children with special needs, as it focuses on advising, consulting, educating and empowering staff to take on special needs and multicultural programming themselves.
- the main aim must be to ensure that all the skills, ideas and resources provided to the centres continue to develop and extend after the SUPS worker leaves. The responsibility of working with children with special needs and children from an NESB should not rest with one person. It must be the responsibility of all child care staff.

Occasionally, we may encounter negative attitudes from the community and child care sector. Some child care centres are not interested in either 'taking on/integrating children with special needs', as it is 'too hard' or 'there are not enough resources in the centre'. Other centres claim that they 'do not need multicultural programmes, as all their children are Australian'. In our opinion, these are the centres that require the most support, and we try gradually to change attitudes by offering disability and cultural awareness training and targeting these people through newsletters, workshops and informal discussions.

We have not experienced any problems regarding the availability of trained personnel and there is a good response during recruitment. It is very important to recruit highly-skilled, trained and experienced workers.

The SUPS programme has no problems identifying and reaching children with special needs, as the model is based on providing support to services that request it – thus it is responsive.

#### LESSONS LEARNED

Lessons learned from the casual ethnic workers pool programme and the supplementary workers programme (SUPS).

- Funding for the CEWP and SUPS programmes must be adequate and on-going. Wages, resources, training and administrative costs are on-going and should be earmarked within the budget, for efficient and effective service delivery.
- Adequate funding is essential for the type of service and support offered by the CEWP programme; the programme provides a unique, practical human resource and 'hands on', bilingual/bicultural support. Lack of funds and limited resources can create frustration and disappointment for child care centres, staff, parents and children.
- In order to establish better access to resources for casual ethnic workers, a Multicultural and Special Needs Resource Van was funded, as a component of the CEWP programme. The Resource Van, driven by a CEWP project officer, visits child care services where casual ethnic workers are placed, to provide resources and support.
- It is important to encourage cross-programme liaison and collaboration. Both the CEWP and SUPS programmes should work together, where possible.
- Children's services need to be clearly informed about the role of the casual ethnic workers, so that they are not misused as simply an extra pair of hands.
- SUPS programmes operate in pools and service large regions. They therefore need co-ordinators to support, supervise, plan, monitor, review, co-ordinate and administer the project.
- The role of the SUPS sponsor has been a major factor in the success of this project. Community-based organisations are effective sponsors of SUPS programmes, as the existing community-based structure enables effective administration of the project. It can offer the support, resources, administrative, equipment and skills of other community-based workers/projects, which may not be available to SUPS workers based in child care centres or municipal councils.

#### CONCLUSIONS

The CEWP programme is a unique, practical, human, 'hands-on' resource which, in its 15 years of operation, has benefited a large number of children, families and children's services through facilitating culturally, linguistically, and developmentally appropriate, quality child care.

Furthermore, the programme is also an excellent stepping stone for people from a non-English speaking background who are interested in developing further their careers in early childhood. As most of the casual ethnic workers are women, it gives them an opportunity to expand their skills and fulfil their potential. Many go on to find part-time and full-time employment in the children's services, welfare, health and other fields.

The CEWP is a cost-effective programme, servicing a number of centres, targeting a large number of children and staff, not just those children with special needs. The casual ethnic worker works with the staff to encourage them to include the multicultural and disability components as an integral part of the centre's operation, planning and programming.

An effective SUPS team will achieve its aims to assist children from a non-English speaking background and children with special needs, to gain access to and have appropriate, quality care in child care services. The SUPS programme is extremely important and vital, in order to facilitate Access and Equity and Multiculturalism in children's services.

SUPS programmes such as the Bankstown Early Integration and Networking Group (BEING), create greater awareness among mainstream service providers and continue to resource children's services staff with the necessary skills to implement multicultural and special needs programming throughout all areas of the curriculum. Support for the integration and inclusion of children with special needs in children's services is also provided to those service providers. The BEING provides a focal point for children's services in the local area, by offering resources, support, advice, information, training, community development and hands-on help, in relation to special needs.

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# Special Educational Needs in early childhood care and education in the Junji (Junta Nacional de Jardines Infantiles) of Chile

#### By ERIKA LARRAGUIBEL QUIROZ

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# PRE-SCHOOL EDUCATION IN CHILE

#### 1. The pre-school population

In Chile, the pre-school population (birth to six years old) is 1,714,810. Of these, 374,284 children (21.8%) attend a variety of state education programmes.

There is more provision for five and six year olds than for younger children. 217,371 of the five and six year olds are in education programmes, whereas only 10,843 children aged up to two years receive this provision.

Forty-five per cent (775,094) of pre-school children live in very poor conditions, and only 29.2% (226,370) of these receive any pre-school provision.

#### 2. Educational policy

During the 1990s, education has been one of the major priorities of the state. Priority is given to policies aimed at overcoming inequities within the sector, particularly for people on a lower income. The aim is to improve their take-up of provision.

In relation to pre-school education, policies aim to: 'Expand the coverage of pre-school education (children from birth to six years old) improving its quality and its links with schools, especially in those sectors of lower income'. The responsibility for extending the coverage lies with the educational centres under the Ministry of Education, JUNJI (Junta Nacional de Jardines Infantiles) and the Integra Foundation.

The social policy is focused on the process of social participation and family promotion. There are now significant advances in reducing: the undernourishment of children; levels of drop-out in the Basic Education Programme (children from six to ten years old); and poverty generally.

Overcoming poverty has been given special priority; within this, education is recognised as being a fundamental factor in the development of the country. In particular, there needs to be equality and better take-up of provision, with a focus on the Basic Education Programme.

In Chile, social programmes have given special emphasis to the family, women as the head of a family and to small children. With reference to the emphasis given to pre-school education: 'it is recognised that all activities developed are effective owing to its [pre-school education's] integral approach, not only for children's development during their key years but also for the family and community as a whole. Such actions have achieved a significant impact, even in their future stages of development'. (Peralta, 1995)

A recent Ministry of Education survey (1995) showed that there has been great investment in infrastructure, materials for children and parents, classroom libraries and training, and an increase in early childhood programmes for children aged up to six.

## 3. Law of social integration for people with special needs

The Law to Integrate People with Special Needs (January 1994) includes all social sectors of the country. There are more than 1,300,000 people with special needs in Chile and approximately 1,000,000 live under poor conditions.

The law establishes that: 'the public and private mainstream education centres should incorporate the necessary innovations and curricular adaptations to enable access for people with special needs, providing them with the complementary education required in order to assure them of their permanence and progress within this system (Law of Social Integration for People with Disability, No.19.284, Chapter II, January 1994).

The National Programme to Overcome Poverty for 1995/2000 states that people with special needs should have priority in receiving provision.

The legislation therefore indicates the necessity for wider coverage and implementation of curricular innovations, together with co-ordinated interdisciplinary support. This support involves the health, justice and education sectors.

#### 4. Families of people with special needs

For several years now, there have been a number of organisations for parents and professionals which have been working for the integration of people with special needs. Such organisations arise from the interests of families and professionals concerned with particular types of disability. These organisations are involved in the development of training, workshops, lectures and documentation. These organisations have had an important role in the support networks.

Poor families, especially those living in isolated or rural areas have almost no medical/psychological care. For example, there are no diagnostic facilities or treatments for children with special needs. These problems are part of the social inequity existing in the country, where there is also widespread rejection and prejudice towards people with special needs.

The role played by the pre-school educational system in integrating people with special needs is crucial, as it has become one of the first opportunities for integration outside the family.

#### JUNJI (JUNTA NACIONAL DE JARDINES INFANTILES)

JUNJI is an independent organisation which was established in April 1970.

Its responsibilities are to:

- i) create, plan, foster, stimulate and supervise the development of nursery schools nationally;
- ii) stimulate, co-ordinate and supervise the public and private pre-school sector, as well as supervise the adequate use of resources assigned by the state to pre-school education.

JUNJI makes provision for 92,014 children, aged from three months to five years, attending 1,300 education centres in the 13 regions of the country. Six thousand employees work in JUNJI, including pre-school teachers, nutritionists, social workers, assistants to pre-school teachers and administrative staff.

JUNJI is the most important educational organisation in the country for children between 3 months and 6 years. Its educational plans contribute to the delivery of the objectives for social development and quality of life covered by the National Plan to Overcome Poverty.

The criteria used to select the children provided for by JUNJI favour those known as: 'families that cannot solve by themselves their poverty conditions and are unable to reach state or private social security services'. (Aranguiz and Jiménez, 1996)

JUNJI also creates innovative educational programmes which enable it to ensure that its activities take into consideration the great range of needs detected in pre-school children. For example, there is the Family Garden programme, run by assistants to pre-school teachers, with the participation of family members. The Home Nursery programme is also run by assistants who work with parents, sometimes in their homes.

In these and the other innovative programmes, as well as in the traditional nursery school programmes, free and integrated provision is made for children from three months to five years of age.

#### THE JUNJI INTEGRATION PROGRAMME

#### 1. Initiation

In June 1995, JUNJI designed a Programme of Integration which targeted the poorest children with special educational needs. This programme has been developed in all thirteen regions of the country, and is included within all other Junji education programmes.

The Junji nursery schools have been taking children with special needs for a long time. The integration programmes also support professionals and specialists who have accepted the challenge of integration.

The programme needed to marry the expectations and theory with the reality of the situation in schools. First, it was important to establish policies and basic working criteria related to:



- roles
- · short, medium and long-term activities
- the conditions needed to create a multidisciplinary working team
- the curriculum
- evaluation methods.

## 2. Design and development of the Integration Programme

The aim of this programme is to: 'Favour and foster children's integration into the educational programmes of JUNJI through short, medium and long-term strategies'. Seven specific objectives were planned.

A description of each specific objective, together with the strategies for its implementation, is given below:

#### Objective 1.

To support the integration of children with special needs who attend the different educational programmes of JUNJI

#### Strategies

- In order to achieve this objective, teachers were 'sensitised' and trained. A monthly bulletin is distributed to JUNJI's educational settings. In each leaflet, different subjects are developed in a simple and pedagogical way, for study and analysis by the parents and teachers in a workshop environment. Twelve bulletins will be published in total.
- Teaching materials were selected, after conducting an evaluation of possible materials in the field. The main criteria applied were: a) that such material should stimulate the children; and b) that it should allow them to participate with other children with or without special needs. The selected material was distributed over a period of a year to the educational institutions which were providing for children with special needs in each region.
- A book of 40 case studies was published. The case studies represented examples of good practice in the field of integration which had been developed by the educational community of JUNJI. There are parents' experiences and accounts from directors and teachers. All of the case studies highlight the benefits of children's experiences of integration.
- JUNJI purchased a video on the integration of children with special educational needs into mainstream schools. Copies of the video were sent to the 13 regions of the country for use by JUNJI staff and by people outside the organisation.
- JUNJI allocated funds to buy books dealing with integration into mainstream education programmes.

Those books were sent to the pedagogical centres in each of JUNJI's regional offices.

#### Objective 2.

To co-ordinate joint support activities between ministries and organisations which favour the integration of children with special needs

#### Strategies

Three joint activities were co-ordinated in order to meet this objective:

- with the **Special Education Department** (DEE) of the Ministry of Education. An agreement was signed between JUNJI and the DEE to entrust to JUNJI the early diagnosis and treatment of children with special needs in all the JUNJI Diagnosis Centres and special schools in Chile. The agreement also involves the development of information lectures and training courses for nursery school staff. JUNJI assists with the development of research and studies which the DEE wants to carry out in its centres.
- with the National Fund for Special Education (FONADIS). This is a state organisation in charge of financing technical assistance such as wheel-chairs, prostheses and hearing aids for those people with special needs who do not have the means to fund these purchases themselves. The agreement is that through FONADIS, the JUNJI can obtain technical assistance when required.
- a mutual support agreement was signed with UNESCO which will provide a three- year training programme for the teachers and directors of nursery schools in the thirteen regions of the country. UNESCO also offered to collaborate on the adaptation of evaluation instruments to record and assess the achievements of children with special needs. UNESCO will also assist in identifying the educational needs of the children, substituting the medical classification with educationally-based definitions of need.

#### Objective 3.

To develop principles and guidelines for the integration of children with special needs into JUNJI's educational programmes

#### Strategies

Library studies were initiated to deepen the understanding of theory, curriculum methodology, others' experiences and the historical background of the integration of children with special needs into mainstream education. From this base, study documents, reading reports and the definition of key concepts have been developed.

Technical guidelines and principles have been developed which provide a practical approach to integration. These guidelines establish criteria for the identification of children with special needs and for the evaluation of these children's educational achievements.

#### Objective 4.

To identify curricular innovations to plan the integration of the children with special needs attending JUNJI's centres

#### Strategies

- Training activities for the Regional Technical Teams (RTTs) have been designed and implemented. The RTTs supervise JUNJI's educational centres and advise on the adequacy of the curriculum within the integration process.
- Subjects such as curriculum planning, family work, work with multidisciplinary teams, and the role of the teacher and other educational agents, have been revised. Specific training has been provided on classroom-based activity with children with mental disabilities.

#### Objective 5.

To identify structural adaptations which are needed in nursery schools in order to facilitate the integration of children with special needs

#### Strategies

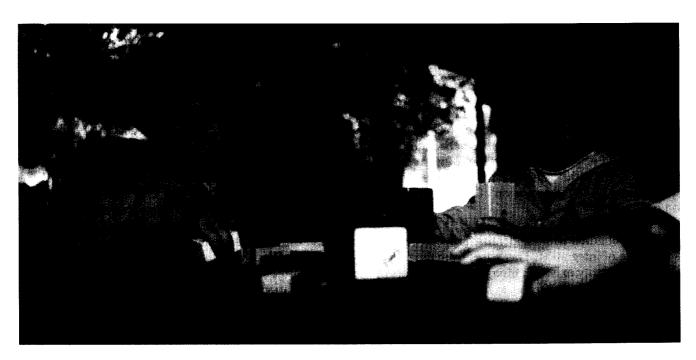
• The structural department of our organisation (architects and civil engineers) has developed a proposal for basic modifications to improve access for children with physical problems to the centres. This proposal will be implemented this year as a pilot project in three nursery schools in the metropolitan region of Santiago. The modifications will be evaluated and then applied in other centres.

#### Objective 6.

To identify financial resources to fund the implementation of the programme for the integration of children with special needs

#### Strategies

Private organisations interested in collaborating
with JUNJI on the integration programme were
offered projects for sponsorship. So far, funding
has been obtained from an enterprise dealing with
teaching materials; this is for publishing the text:
New Experiences in Integration. UNICEF has
collaborated on the provision of teaching materials
and has part-funded training staff who provide
training in the regions.



• At the time of writing, some projects are being presented for funding to other institutions and agencies. These projects are to provide regional training, to assist with structural adaptations and to develop seven videos for a training programme.

#### Objective 7.

To evaluate the different strategies applied in order to inform future decisions about the Integration Programme

#### Strategies

- Different evaluation instruments were designed, relating to the specific objectives and strategies outlined above, and taking account of the terms and timescale for their implementation.
- Evaluation guidelines developed by the National Technical Department are being sent to the nursery schools.
- The results of the evaluation were positive in that all the activities proposed were accomplished within the terms and timescale agreed. The personnel working in the nursery schools felt that these activities were very useful and necessary in their daily classroom work; they have appreciated this contribution to their professional practice.
- A 'diagnosis' evaluation of the integrated children has now been developed. It was proven that more than 40% of the children with special needs attending nursery schools entered the JUNJI this year. This indicates clearly the achievement of the Integration Programme to date. The results are highly satisfactory, especially given that implementation of this programme only began in June 1995.

#### 3. Field evaluation

The above information provides a general view of the design and development of the Integration Programme over a period of a year. The programme continues to develop and has some new strategies which have been adopted to ensure that it continues to do so. This continuity and advance has been possible because of the on-going self-evaluation of the nursery schools and the close contact maintained with the teachers in the centres.

A second important method of evaluation is being developed through monthly regional meetings, where we discuss what is happening in the classrooms and develop support mechanisms for dealing with the problems which emerge.

In addition, observation visits to the nursery schools are organised, when there is discussion with the parents and families of the children, as well as meetings with the nursery school staff.

In this way, an objective overall evaluation of what is really happening can be obtained, which facilitates good implementation of future decisions.

# 4. Attitudes of the educational community

It is important to share the attitudes of the educational community and the children's families towards integration. Most of them are open to the idea of integration and are well-disposed towards it. Teachers and staff share with their colleagues both the personal and professional enrichment they have derived from this work.

There are still individuals who are reluctant to share with different people. This is often a consequence of attitudes of rejection which have been maintained over a period of years. It is therefore of great importance to develop the 'sensitisation' work through frequent contact and the provision of current information on integration.

Parents of children without identified special needs are supportive of integration. This arises from the framework of solidarity existing among the poor sectors of society. They feel themselves to be socially excluded; this kind of experience helps them to develop positive attitudes towards 'difference'. For them, accepting children with special needs occurs naturally, as part of their feelings of solidarity.

For the JUNJI children, any classmate is someone with whom to play, share or disagree. They do not feel barriers, they act naturally and without prejudice. It is children who best embody the meaning of living in a society where each person has a right and the opportunity to participate.

Results obtained through a survey of families of children with special needs show that most of these families (64.7%) have a supportive attitude towards their son or daughter, and that they are therefore committed to helping him or her achieve their potential. Twenty per cent of parents have an overprotective attitude towards their children with special needs. Just under 14% of parents are indifferent, and 1.7% reject their child with special needs.

#### 5. Summary of achievements

At present, JUNJI has integrated about 600 children with special needs which is equivalent to 0.6% of the total number of children for whom it provides (92,000). Most of the integrated children are between four and six years of age (74.3%) and they are mostly boys (56.2%). They have a range of special needs, including physical, mental, visual and hearing disabilities.

The Integration Programme delivers quantitative data which show that almost 40% of them were integrated during one year, which means a great success for the Programme itself.

#### MAIN DIFFICULTIES AND PROBLEMS

The main problem we are currently facing is the acceptance of integrated children from JUNJI into the mainstream basic education system, which is the level that follows pre-school education.

Once children who have been integrated at nursery leave school, they have no chance of being accepted in mainstream basic education schools.

Another difficulty is the lack of financial resources. The initiation of the integration process into the mainstream education system needs additional funding. Resources are needed to purchase teaching materials and technical documents, to physically adapt the buildings, to provide training to both professionals and parents and to contract specialists.

There is also a need for an organisation or institution which can co-ordinate the different activities and integration experiences already developed at a national level. Such an organisation would establish support networks for other organisations working in this area, to enable them to share their successes and difficulties. This would then contribute to the development of integration.

#### LESSONS LEARNED

Much has already been learnt. The key points affecting the work described in this paper are outlined below.

Participation in the programme was voluntary for both teachers and technical officers. The principle underlying the programme, that each citizen has the right to feel part of society, without discrimination, was underlined. JUNJI's experiences in integration practices led it to ensure that participation in the Integration Programme was not obligatory. JUNJI has also identified the need regularly to provide information to 'sensitise' those who are reluctant to become involved in integration and to reinforce those already working in it.

JUNJI has not given any guidance on the level or type of disability which it is feasible to integrate. This has been of benefit to children with very severe disabilities who have integrated successfully – eg. blind and deaf children.

This has allowed the children (either with or without special needs) to utilise innovative communication systems and adaptation strategies. They make up for deficiencies using other senses and develop skills and abilities which compensate for them. Individual language codes are developed which quickly become 'the norm' in interaction between classmates. There is no peer segregation in the classroom of children with special needs. They welcome and interact with people who do not conform to a limited definition of 'normal'. It is possible that in the future, children who have had this integrated experience, will be able to integrate everyone into society, taking into consideration each one's individual contribution.

From the teachers' point of view, integration has meant entering a valuable field of rich professional experiences. Horizons have been widened and new and learning experiences encountered. The teachers have learned to differentiate classroom activities, plan and evaluate curriculum, discover new potential in the children, and to deal with difficulties in controlling and supervising the children to ensure that they can succeed.

The knowledge obtained by the teachers in the field would have been impossible to acquire in most specialised courses.

The prospects are that there will be a continuity for this work and its activities which are recognised as adding to the values of Equity and Quality for all children coming from poor sectors, especially those with a double risk, those with special needs.

More important than any of these lessons is the fact that the educational community of JUNJI is growing in a personal and professional way within the Integration Programme. We feel glad to be able to share it with other persons and organisations interested in knowing about this type of educational experience.

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# Roskilde County's Services to Young Children with Severe Disabilities

By SPECIALRÅDGIVNING FOR SMÅBØRN, ROSKILDE AMT

# DESCRIPTION OF THE ORGANISATIONAL STRUCTURE OF ROSKILDE COUNTY

Denmark has a population of about five million people. The country has a two-tier system of local government, being divided into 14 counties and 275 municipalities. Both levy income-taxes. The county of Roskilde is geographically small, and rather densely populated, with 220,000 inhabitants. There are 11 municipalities in Roskilde and about half the population lives in just three of these. The remaining seven municipalities are predominantly rural.

Delivery of many services in Denmark is shared by a county and its municipalities, each covering specific areas of responsibility. In the field of special education, county and municipal responsibilities are closely intertwined. In the social field, the county has an obligation to provide advice and a policy lead, while the municipalities are responsible for practical/economical assistance. The county is required to offer special pedagogical assistance to the child and his or her parents until the child begins school, and this is provided free of charge.

About 1% of Danish children are born with a severe disability. As the number of children with severe disabilities is relatively limited, services are provided across a county area and it is usually the counties which employ specialists to assist both the municipalities and the children and their parents.

Roskilde County has a large number of creches and kindergartens which are run by the municipalities. The county itself runs two special kindergartens for young children with disabilities; one kindergarten which is open during weekends and two smaller institutions which take the children for respite care. In addition, the county also runs two residential establishments for children who cannot stay with their families.

By law, all disabled young children in Denmark are entitled to education and social assistance. In Roskilde County, education and support for disabled children and their parents is offered until the child reaches school age (at six years). A multi-disciplinary team is employed by the county and comprises specialist early years advisers, a psychologist, a paediatrician, a sight-therapist, social workers and a special education adviser. If the child has a disability which is beyond the scope of the multi-disciplinary team, he or she is referred elsewhere to the appropriate specialists.

# THE SPECIAL ADVISORY SERVICE FOR YOUNG CHILDREN WITH DISABILITY

#### 1. The aims of the service

The arrival of a child with a severe disability fundamentally alters the life of any family. Living and developing with a severely disabled child requires continuous foresight, flexibility and reappraisal as the child, the family and the society in which they live change and develop.

It is now accepted that the disabled child's chance of living a 'good' life does not solely depend on the degree or the nature of his or her specific disability. The family's ability to cope with living with a disabled child is just as important, as is the way in which society views and meets the needs of disabled children and their parents.

This vision of disability, coupled with the knowledge that early intervention provides the best chance of achieving a child's developmental potential, means that the Special Advisory Service for Disabled Young Children has a twofold job:

- first, to reinforce the parents' role and responsibilities and to enable them to cope with the task of living and developing with a disabled child. The work with parents is given high priority; they are seen as the most important resources in the lives of their children and are the only people who are permanently present in the child's life.
- second, the team ensures that an early, multi-disciplinary and well-coordinated intervention is started and maintained. The aim is that the intervention process will gradually be taken over by professionals working at municipal level. This will certainly be the case by the time the child starts school. The county team discusses goals and outcomes with the municipal team to enable them to take over at the appropriate stage.

The county describes its policy as follows:

'Starting from the general social aim of giving disabled persons a life as close to normal as possible, the county works from the basic assumption that everyone – regardless of the degree of their disability – is a citizen of equal dignity, with a right to the same quality of life as others. That means that they should have the right to housing, education, medical and other care, employment and opportunities for development.'

#### 2. Service provision

Assistance to children and their families includes:

- direct, home-based pedagogical counselling
- the establishment of individual plans for education and care, comprising communication, interaction and daily living
- making suitable day-care available
- advice and counselling for parents
- respite care provision
- grief/crisis therapy for parents
- counselling for staff in county and municipal institutions
- training courses for parents and grandparents
- weekend seminars for parents
- toy-lending
- warm-water-swimming for the children.

# THE FAMILY AND THE YOUNG CHILD

#### 1. The family situation

As mentioned earlier, the parents of a disabled child are placed in a life situation which will often bring severe pain and complex problems in connection with the care and upbringing of their child.

The parents of severely disabled children are forced into crises that never end. The grief and distress recur each time there is a relapse, or when their child reaches a stage of transition, such as starting school, leaving school and leaving home. Parents may need professional assistance to help them cope with their feelings and reactions, in order to be able to manage their lives and cope with the problems they have to face.

Likewise, parents need the expertise of the professionals in order to learn how to stimulate their disabled child. Parents' knowledge of how best to stimulate and support a child's development is usually insufficient if their child is severely disabled. The parents of our severely disabled children most often require qualified and comprehensive advice as to how they, as a family, can best support the positive development of their particular child. They need and demand precise knowledge about their child's specific disability and about his or her limitations and potential. They need very concrete advice on how they can best stimulate their child, and yet remain parents.

Usually, the greatest difficulties families face are: coping with people's reactions (shocked, aggrieved relatives, prejudice of strangers in the street, etc.), having to adjust to a new set of circumstances, their dependence on 'the system' and the assistance they receive or don't receive. When a disabled child arrives, the family automatically becomes a part of – or user of – the social services system, though under normal circumstances the family would never have needed public support. The family has to learn to find its way around the system and to cooperate with a large number of professionals. Just participating in meetings with pedagogues, home counsellors and teachers, and seeing doctors, physiotherapists and so on, can put considerable strain on a family.

In Denmark, there is now general agreement that an early, well-coordinated, holistic and multi-disciplinary intervention is a requirement if a disabled child is to develop to his or her maximum potential. Adhering to this policy and organising its delivery is very demanding on the system. Unfortunately, the parents often find the coordination of this service inadequate. In several country-wide surveys, parents have stated that this specific part of the service is completely inadequate. They state that often they themselves have to take on this coordination, which is an enormous extra undertaking, partly because of the time it involves, but probably mainly because they do not know enough to find their way through the system. The parents complain that they do not get sufficient information about their rights and to what services they could have access.

# 2. Cooperation between the county and the municipalities

The county has worked in cooperation with the municipalities many times and generally found these experiences to be positive. There is direct cooperation over individual children and their families, where the county team's expertise is used appropriately and the division of labour between municipal and county staff is agreed on the merits of the individual case. This means that municipal staff undertake areas of work they are able to shoulder adequately.

The experience of members of the county team is that the professionals in the municipalities appreciate and use the advice and guidance they provide. The expertise of the Special Advisory Team is seen as a necessary and important complement to the work of the municipal teams. The cooperation is unproblematic, and new joint initiatives are often developed between the county team staff and the municipal professionals.

The municipalities often apply for various training courses for their staff or suggest new initiatives; for example, working with parents to set up parents' groups or networks for parents with disabled children.

The 11 municipalities have very different requirements of the Special Advisory Service, both qualitatively and quantitatively. The smallest municipalities are the greatest users of the team's services; sometimes a particular unit can be too small to contain the necessary experience and expertise. The smallest units, despite the best intentions, cannot cope with all the different areas of work.

In the past few years, in order to get the best use of the experience that has been accumulated, the larger municipalities have established disability teams. This work is viewed positively by both parents and politicians, but is in reality limited by a shortage of resources. The aim is that services should be delivered at as local a level as possible, but apparently we are facing a movement back towards the larger municipalities again considering use of a central team, because of a shortage of resources.

There is no doubt that a lack of resources impacts on early intervention and that economic considerations often overrule the pedagogical ones in deciding if and to whom early intervention should be available.

It can often be difficult to ensure that staff responsible for the day-to-day work are kept up to date. Team members can advise and supervise, point to areas where training is needed and sometimes deliver the training, but if time and money are not made available, the question is again: how can we solve the problem in the best possible way within the available resources?

# 3. Methods for early diagnosis of the young child

When a child is born with a visible disability, is premature or ill at birth, the hospital notifies the relevant municipality and ensures that it is aware that the family will need assistance. For children who do not show signs of problems at birth, it is the parents, the health visitor and day-care staff who will observe that the child is not coping as expected.

Once the municipality has been alerted to the presence of a disabled child, a social worker will investigate the material needs of the family, and a person from the pedagogical/psychological service (PPS) will investigate the child's need for special pedagogical assistance.

At this stage, the PPS often contacts the county early years advisers who, together with a psychologist and a health visitor, contact the family and establish an overview of the developmental problem.

The developmental problems of the child, and what pedagogical assistance he or she needs, are uncovered through talks with parents, health visitors and our own observations. Besides various tests, 'development descriptions' are created, which describe the assessors' perceptions of the child's difficulties and, very importantly, highlight the child's strengths and developmental potential.

The motor-perceptual development description is a neuropsychological/neurophysiological observation. It was developed by Britta Holle et al in 1977. The observation material was standardised using 1,206 'normal' children, and is, despite its age, still much used by physiotherapists and pedagogues.

The developmental description gives the background for a thorough observation that can help the pedagogue chart the child's potential for development from dependence to independence and autonomy. It enables you to see the child's difficulties and potential, and to identify his or her 'developmental zone'. The pedagogical work can then be planned on the basis of this assessment.

We also use **Kuno Bellers' development description of young children** which was translated and adapted for Denmark by Hans Weltzer in 1984. This material is not standardised.

In our daily work with severely disabled young children we use publications, films and lectures from the Knowledge Centre for Children and Youngsters With Multiple Handicaps and Without Verbal Language. Led by senior lecturer Birgit Kirkbæk, this centre has gathered and coordinated knowledge about pedagogical methods which have been developed, tested and analysed by Danish teachers, pedagogues, physiotherapists, ergotherapists etc.

We know that all human beings are born with the potential for communication and interaction with their environment and this is one of the fundamental principles of our work. We spend a lot of time uncovering the child's potential for communication, investigating the child's ability to use eye-contact, pointing, using sounds or self-made signs.

When we observe that the child has severe contact problems, we will investigate the child's social development and his or her communication and interaction skills. If there is also deviant behaviour, we will refer the child for investigation for autism or other severe

developmental disturbances. These tests are done at the Centre for Autism and/or paediatric hospital departments.

#### 4. Daily work in the home

Early stimulation and pedagogical intervention are started as soon as possible after identification of a child's disability. The early years advisers assess and describe the child, and, together with the parents, develop stimulation programmes for the child. The parents are the key people in the life of the child and it is therefore important that they understand the pedagogical intervention and that it takes account of the family's psychological, emotional and physical resources.

The family is visited according to its needs, usually once a month. During the visits, the adviser and the parents play with the child, and the development of the child and the family since the last visit emerge through observation and conversation. In early intervention, the accent is placed on the development of the child's communication skills and the interaction between the parents and their child. When discussing our observation with the parents, we thus put the accent on the child's strengths and on the positive experiences the parents describe. Where the child expresses pleasure and seems to be doing well, we suggest new areas for stimulation. To further the development of the child's ability to communicate, we show the parents how alternative means of communication (e.g. sign-to-speech, the Bliss Symbol System, body-language pictures and use of sensory materials) which can support and further the child's understanding and develop his or her ability for selfexpression.

During the visits we introduce suggestions for play and other activities which can stimulate specific development areas, and the parents are able to borrow toys and other resources. They also have the opportunity to participate in warm-water-swimming, which includes guidance on developing the child's motor skills and how to further the development of communication skills/interaction through playing in water.

During the home visits, parents can also discuss the everyday life of the family and can raise any problems related to the general upbringing of their child: eating, sleep problems, relationships with siblings etc.

There are also frequent progress meetings between parents and professionals during which the whole programme is discussed and the need for supplementary education and treatment is assessed.

#### 5. Courses for parents

Once a year, the Special Advisory Service arranges a weekend seminar for whole-family groups. There are places for eight families with disabled children of up to two years of age. The aim of the seminar is to give the parents the opportunity to meet and exchange experiences, and to give the parents some 'tools' which will help them to handle their new life. An important part of the seminar is to talk over the feelings of grief and crisis which accompany the arrival of a disabled child.

While the parents are taking part in the programme, their children are looked after by respite-care staff, and older siblings have activities arranged for them.

In addition, parents and pedagogues are taught sign-to-speech and attend seminars on a wide range of pedagogical issues, including sessions on lifting techniques, the Peto method (conductive education) for children with motordisabilities, swimming etc.

The early years advisers run a regular seminar on 'play-contact and communication'. This activity takes place once a week during winter and focuses

on interaction between parents and their disabled children. Parents attend with their disabled child and work on this area with the instructors. Video-recordings of parent-child interaction are made and used as a basis for discussion.

#### 6. Grief/crisis assistance

The grief/crisis assistance is therapeutic assistance, which can be provided during individual sessions with the parents or in groups. Parents are offered assistance in dealing with their grief over the arrival of a disabled child. They receive guidance on how they can live as normal a life as possible with their disabled child.

Our attitude is that parents of disabled children are normal people like you and me. Their basic confidence in life has been hit, i.e. their whole existence has been shattered. They have suddenly lost their illusion of control and invulnerability, and have thus had to realise that life carries no guarantees. The aim of the grief/crisis assistance is to help the parents regain their confidence in life and to help them to live with the difficulties associated with the birth of a disabled child.



#### 7. Grandparents' seminar

Over the last four years we have also offered seminars for grandparents. They are a great success for all concerned.

Once a year, the Special Advisory Service arranges a four-evening seminar for grandparents of disabled children. Like the parents' weekend, the aim is to give grandparents the opportunity to meet and exchange experiences. The taught programme is the same as that for the parents. One evening is reserved for giving the grandparents ideas on how to play with their grandchild.

From time to time, grandparents are offered courses in various subjects; for instance, in how to communicate with a deaf child.

#### 8. Respite care

We believe that parents of very demanding children – and severely disabled children usually are very demanding – should be relieved from caring for their child for at least one evening a week, one weekend a month and for a vacation period of three weeks a year.

Respite care, or 'relief stays' can be provided in one of the county's relief institutions or with relieffamilies, employed by the municipality. Another type of relief can be the provision of practical help in the home; for example, with cleaning.

If the breathing spaces provided by the respite care are insufficient, the families may instead need residential care for their disabled child. Contact with the home is maintained, with the child going home whenever the parents can manage it. There is a close cooperation between the residential institutions and the parents, including a joint approach to the child's daily life.

# THE STAFF OF THE SPECIAL ADVISORY SERVICE FOR YOUNG CHILDREN

#### 1. Professional background

The Special Advisory Service for Young Children is staffed by professionals from a wide range of disciplines and training backgrounds. Members of the team come from the education sector, the social sector and health services and they have usually been trained as special pedagogues, social workers, doctors and psychologists. The team members share a professional interest in and focus on the field of disability.

Given that many parents experience a lack of coordination between the various experts, the Special Advisory Service sees it as part of its work to ensure the development of multi-disciplinary working methods with its partners in the municipalities. This is done partly by adopting best practice when working with individual cases and through seminars for various municipal staff.

#### 2. In-service training of staff

The staff of the Special Advisory Service all have experience from previous employment in the municipalities. They thus have a considerable cultural knowledge on top of their specific professional expertise and use both in their counselling and guidance of the staff in the municipalities. Being employed in the county's Special Advisory Service for Young Children implies that there is on-going postgraduate education and training to maintain an up-to-date knowledge of developments within the relevant areas of practice. This happens through participation in conferences and seminars, and contacts with national resource or 'knowledge' centres and colleagues working in similar areas. The exchange of experience between practitioners and theoreticians is also important. Securing a combination of theoretical insight and practical research/empirical evidence is facilitated by the weekly internal meeting in the Special Advisory

Service. Where the need for further training is identified, the necessary funds are normally made available. For example, the two social workers have just completed training as grief/crisis therapists, and the psychologist is undergoing postgraduate training to be a supervisor.

### 3. The staff's cooperation with other institutions

The early years advisers cooperate with institutions outside the county, such as 'knowledge centres' which have the latest information about a wide range of disabilities. In our work with the parents, we use publications, films and lectures from the knowledge centre for children with multiple disabilities and without verbal language.

This centre has collected and coordinated knowledge about pedagogical methods which Danish teachers, pedagogues, physiotherapists, ergotherapists etc. have developed, tested and analysed.

# THE SPECIAL ADVISORY SERVICE'S AIMS FOR FUTURE WORK

# 1. Visions for future work with disabled young children and their families

As can be seen from the above, the challenge of providing a holistic, well-coordinated intervention for severely disabled young children has not yet been met adequately. High priority is given to improving this situation and to training the staff in the municipalities to assume responsibility for the service.

The ultimate goal is to ensure a life that is as close to normal as possible for our disabled fellow citizens. This is attempted through a holistic, coordinated intervention which occurs 'horizontally' as well as 'vertically, i.e. from infant to adult and across profes-

sional and administrative boundaries. When the Special Advisory Service for Young Children is giving advice and counselling, it also takes the child's coming school-life and life as a young adult into consideration. The county hands over responsibility for the disabled child to the municipalities when he or she reaches school age. The Special Advisory Service always has this in mind throughout the early years, training municipal staff and passing on the principle of close cooperation between parents and professionals.

For several years now, Roskilde County has been developing its services to parents, realising that parents who feel good are better able to cope with the extremely heavy burden of bringing up a severely disabled child. The continuing development of these services is given the highest priority.

We aim to make a gradual change from providing advice and counselling in the home to giving advice and counselling in small groups. In this way, we hope to strengthen the formation of networks between families in similar situations. Many families with disabled children find that their network of family and friends slowly disintegrates: our alleviation of isolation and loneliness focuses on developing and working with networks. The county's effort in this respect also includes the establishment of grief/crisis groups, seminars and conversation groups, with subsequent evaluation, so that the parents' experiences and needs are taken into consideration when planning the next round. Further, the county's provision is constantly adapted to the needs and wishes of parents, identified through parent interviews.

The hope and the aim are to strengthen the families, to make them even more able to cope with the upbringing of their children, to enable them to find their way through the system more effectively, to know their rights and voice their claims. Active, articulate parents are good cooperators! We are now able to identify a trend which shows that parents of disabled children are more conscious of their rights and better able to speak up against the system. Reinforcing and developing this is a challenge for all professionals, a challenge which we seek to meet in part by further strengthening the networks which have begun to give parents a voice.

**FRANCE** 

# The Integration into Nursery Schools of Young Children with Special Educational Needs in the Haute-Garonne Department

By FERNANDE VALÉRIE FLAVIER

Audrey, France, Aline, David, Myriam, Pierre, Sébastien and many others come to mind. Each name brings back a story, a life, a child and his or her family, who agreed to let me travel some of the way with them. However far back the first step goes, I have not forgotten that it was thanks to them that I truly grasped the meaning of many words like tolerance, difference, solidarity, citizenship and democracy.

This paper describes early years integration work in the Haute-Garonne department of France and discusses some of the issues informing and arising from that work.

# THE LEGAL FRAMEWORK, A POLITICAL WILL: SCHOOLING FOR ALL IN FRANCE

The schooling of **all children** living on French soil takes place within a favourable institutional framework. The 1989 Education Act established the principle of a right to education, guaranteed for everyone from the age of two in districts included in Priority Education Zones, and from three onwards everywhere else. Article 1 of the Act makes the educational integration of children with disabilities one of the responsibilities of public (state) education, to be discharged in co-operation with schools themselves and health-care services; it is a crucial factor in the educational, social and occupational integration of those with special needs.

The term used in France is 'pupils in difficulty' and this covers children experiencing cognitive or behavioural difficulties, but does not touch on the realm of mental disability involving intellectual 'deficiency' or severe psychological disorders. The standards adopted are based on the World Health Organisation's classification of impairments, disabilities and handicaps.

A rapid overview will give us a few reference points prior to 1989. In June 1975, the Act governing measures to be implemented on behalf of disabled people laid down their fundamental right to education, health care and employment. Integration became a priority; it was seen as the nation's duty to achieve integration. The existing support facilities were to be supplemented by arrangements for assistance in the normal surroundings of persons with special needs. The cost of this policy of inclusion was borne by the state, local authorities and sickness insurance funds.

Since 1975, the relevant ministries have brought their services into line with this policy. For example, the Ministry of Education issued circulars on integration in 1982, 1983 and 1991. In the latest of these, integration is interpreted as the right to mainstream schooling and is linked to the right to care, defined as educational and therapeutic support. Educational institutions have a duty to admit all pupils from their sector, including those with special needs, and are required to plan accordingly. The children with special needs and their families work with the professionals on drawing up an individual educational and therapeutic strategy, setting the goals and determining the resources that will be needed.

The principle of schooling for each and every individual has called into question the tendency towards standardisation in the organisation of the education system. It is now recognised that there is a need to adapt the educational environment to make interaction, and therefore learning, possible. The idea of standardised outcomes is being replaced by a differentiated approach working with scales of achievement. The 1989 Education Act highlights this aspect: 'The right to education is guaranteed for all individuals to enable them to develop their personality, to raise their standard of basic and further training, to take their place in social and occupational life, to exercise their citizenship'. As we can see, political will, organisational patterns and financial guidelines all exist and there is a clear trend towards philosophical, social and economic insistence on integration and the acknowledgement of special educational needs. Yet a closer look will show that, despite the enabling legal framework, implementation varies from one region to another, from one town to another, and even from one school to another in the same neighbourhood. Can it be that attitudes carry more weight than the law?

How can we best move on from mere observation and convince people that, quite apart from any question of obligation, an integrated approach is the best way of educating all our children? Perhaps by backing up the educational teams and, more than anything else, by publicising examples of good practice. Ignorance, misapprehension, lack of information and even misinformation are the biggest obstacles to a policy of education based on fellowship.

# SCHOOLING FOR EACH AND EVERY INDIVIDUAL

# 1. Special needs education in the Haute-Garonne

The Haute-Garonne department includes Toulouse, which is the fourth largest French city, the second academic centre and a growth area for research and technology. The department has over 180,000 pupils from two to 18 years of age (baccalaureate year), including 40,000 in public and private nursery schools.

There has been a policy on special educational needs for a long time in this department; the first institution for the deaf and dumb dates back to 1826. Today, there are 39 specialist establishments for children with

mental disabilities, whether motor or sensory. The policy of inclusion in an open setting began in 1973. Various types of special classes operate in the mainstream school environment, at both elementary (primary) and secondary level. Children with special educational needs therefore have access to education and every effort is made to correlate their educational provision with the care they require.

Furthermore, individual instances of integration have been proceeding apace. The ideal is that children with special needs should attend their local school, which is given the means of making the adaptations necessary to ensure that children with special needs can be educated there.

In 1995-1996, over 800 children recognised as having special educational needs attended nursery or elementary school; this does not include pupils with learning difficulties or immigrant children, for whom other support arrangements are in place.

One of the principles involved in this approach to education is that of long-term commitment. Children with special educational needs, and their parents, must feel confident that the answers put forward have nothing short-term or provisional about them; they must be able to invest in the future, in the knowledge that the notion of integration, and the means of achieving it throughout the various stages of education, are here to stay.

#### 2. Early years education

In the Haute-Garonne, the school enrolment of children from two to six years old is straightforward and the proportion of children enrolled reaches 100 per cent by the age of four. School attendance is very good, even in the case of infants. Children up to three years old are provided for in one of three ways: in the family home or that of a registered child-minder; in day nurseries; at the state nursery school. Since the latter is the only form of provision/care which is free of charge for parents, the demand is high. Furthermore, the information given to parents about the value of early schooling and its links with educational achievement prompts parents to enrol their children very early.

The Haute-Garonne department possesses specialist support and care facilities for young children with disabilities. However, the health and medical-social authorities pursue the same goal of integration in everyday life and therefore assist parents in their search for a nursery school which will accept their child as soon as he or she is old enough. The enrolment process is then carefully organised. Meetings are

held, an integration scheme is drawn up and special arrangements are made, covering:

- the adaptation of premises
- material assistance
- consultancy services
- organisation of the child's time
- content of the educational programme
- health care.

The approval of this scheme by the special education commission guarantees respect for the rights of the child regarding his or her education and health care.

In other instances, when a child with a disability or suffering from a chronic illness has never had the benefit of public child-care services, the parents themselves go through the process of enrolling the child in school. Nowadays, few parents fail to seek help for the problems that come with a disability, even when the disability is not obvious. Nevertheless, it sometimes happens that on the first day of term, a new child arrives who has very serious physical or psychological difficulties about which the school has not been told, despite the parents being perfectly aware of their child's special needs. This remains the exception: the medical and social services do excellent back-up work in gaining acceptance for and coping with difference in the lives of young children.

When there is no health-care service involvement in managing the disability, the educational team assists the parents in ensuring that the work of the school and of the health-care service complement one another. The first questions are always about achieving inclusion in the school system. Is it the best educational response? Is there no more pressing priority? Are the necessary physical alterations to the school feasible? Will the school management be equal to the task? Are neighbourhood services capable of coping with the medical emergencies that may arise in the case of diabetic or haemophilic children?

Time has shown that very few obstacles remain. The local planning authorities have always come up with the necessary resources for alterations to premises, adaptation of equipment and supervision. The educational teams have understood, aside from their obligation to apply the law, the educational value for each and every person of being in a mixed learning community. If some teachers query their ability to cope with a child with special educational needs, this is a good thing. The institution must be capable of responding by giving them the necessary assistance, particularly in the realm of specific teaching techniques. This is the role of the support teachers who originally worked in the specialist establishments; some of these teachers are now assigned to the

integration back-up services. Another response lies in training. One of the centres specialising in the area of visual impairment regularly offers training for teachers in mainstream classes catering for visually-impaired children.

## 3. Detection and diagnosis

It should also be noted that school is usually the place where disability – or a degree of difference that calls for special arrangements – is revealed. How is this first diagnosed and how can schools cope with it?

It is usually the child's class teacher who perceives the first signs, in the shape of clumsiness, susceptibility to fatigue, lack of attention, isolation, listlessness, inability to memorise and other symptoms. If something is to be done about it, the teacher must first raise the issue. The course teachers' councils (which are charged with the follow-up of the children in each educational cycle in order to ensure the coherence of educational policy) can provide initial assistance and the school has a number of resources available to help it in approaching the problems. First, there are the parents, who have to be involved; nothing can be done without them, not only from a legal standpoint, but also from an ethical and a practical point of view. Doctors have an essential part to play in detection: child-health doctors in the case of infants, and school doctors thereafter.

Nursery schools are also able to call upon neighbourhood resource persons, including members of special assistance networks for pupils with learning difficulties, educational psychologists, remedial teachers or rehabilitation instructors. Their work in nursery schools is of an essentially preventative nature; they try to prevent an initial difficulty from becoming a major problem, but also assist in decision-making if it proves necessary to reorganise a child's schooling. Such staff were at the forefront of efforts to support educational teams when young children with disabilities were first included in nursery schools. This was before back-up services were organised on the basis of specialist institutions or health-care services. It was also before it was fully realised that, even in the case of infants, partnership was needed between the health-care services and teachers.

Before presenting the two essential forms of integration in nursery schools, we can outline the various stages in the process of adapting schooling to the needs of the individual child, as practised in the nursery schools of the area for which I am responsible. It is a proposal, rather than a model, respecting legal procedures and involving the school's partners.

# 4. The process following identification

This would be the process if a teacher encounters professional difficulty because of a child clearly requiring special needs education.

## Possible courses of action:

- a) Evaluation of the deficiencies in the child's schooling brought about by this situation.
- b) Educational solution sought at classroom level
   e.g. adaptation of educational approaches,
   differentiated teaching.
- c) Study of the child's case at a course teachers' council meeting: possible solution within the school through differentiated teaching, with assistance for the teacher if necessary.

  At nursery school, it is important not to overdramatise what might simply be a case of psychogenetic development being different from 'the norm', where there is no question of this 'lag' or 'difference' becoming permanent.

  If there are unmistakable signs of the need for psychometric and clinical assessment, the procedure continues, with the authorisation and
- d) Involvement of relevant professionals/services.

co-operation of the parents, as follows:

- The special assistance network for pupils in difficulty, for observation and assessment.
- The doctor concerned, to give a full medical check-up.
- The social services, to provide information and family support if necessary.

These three steps are not simultaneous; they depend on the information received in the process of identifying factors which will contribute to the choice of a suitable course of action.

- e) Review to decide on future action:
  - mainly instructional assistance
  - mainly remedial assistance
  - input for an out-of-school consultation
  - identification of partners for inclusion in the school system.
- f) Examination of the file by the special education commission, for validation and release of the necessary resources. This is the district or departmental commission, as appropriate.

  Presented in this way, the procedure looks cumbersome and formal. In reality, each stage represents a time of exchange, discussion and soul-searching. It is never easy to take decisions that change the course of a child's life and, indeed, of a family's life. As soon as this process begins, the path followed by such children becomes an extraordinary adventure. It is, of course, with the intention of helping them that we undergo this process, yet it

is important to try to ensure that the situation is not over-dramatised and that this intervention is not too early. The academic challenge can all too easily affect the psychological balance of these children, who receive so much attention and yet are unlikely to play a central role in their own 'story' when they first enter the social scene. There is nothing wrong with soul-searching, as long as it does not inhibit action by educators, and such action has to take the form of continuous assessment of the integration process. Assessment is a difficult exercise, which should focus on objective indicators, while also taking account of emotional factors.

# EXAMPLES OF GOOD PRACTICE

# 1. Individual inclusion in a mainstream class

'The nursery school occupies a special place in the overall facilities available for young children. Being complementary to family education and a preparation for elementary schooling, it is the source of essential experience and training that helps children to "grow up".' (Primary school curricula, 1995.)

Clearly, all children need the experience described above. They are taken into a community in order to enhance their ability to communicate. Socialisation is as important as the learning of language. The nursery school is a place of discovery and action. 'Living together, learning to speak and to construct one's language, making a start with the written word, taking action in the world, discovering the world, imagining, feeling, creating' (Programmes of the primary school, Decision of 22 February 1995 fixing the programme for each educational cycle at the primary level): all these seem to be relevant objectives for children with disabilities as well. At this level there is no need to think in terms of adapting the system.

The mandate given by the nation to its nursery schools therefore enables the great concept of integrating all children to be put into practice. At the same time, it does not rule out special provision for those in need of it.

A personalised approach is therefore the key to individual integration, whether those concerned are children with disabilities as classified by WHO or children suffering from severe chronic illnesses.

## The process of integration

The first stage will depend on the origin of the request for integration. If it comes from the family, there will have to be an initial period of investigation and information-seeking to make sure that any action is based on a full knowledge of the facts. Account will also have to be taken of the response of the teachers. It is known that a positive response from the class teacher encourages a supportive attitude in the other pupils and therefore makes for more successful integration.

After an 'observation' period and confirmation that conditions are manageable for both the child and the school, the head calls a staff meeting, to which the parents and partners involved in health-care provision are also invited. The resulting personalised plan constitutes an agreed contract between them, which is both a moral commitment to and clear plan for the active promotion of the child's development.

Individual cases of integration do not always call for a major mobilisation of resources within the nursery school. Care must nevertheless be taken to ensure that the children genuinely participate in the learning process. For example, deaf children will need an effective means of communication in order to pursue their studies. Blind children will need help in finding their way around; they will have to be assisted by clear oral communication, make a first acquaintance with the written word through Braille, and receive special tuition in recognising objects by touch. For children with motor disabilities, care must be taken in formulating the concepts of time and space. These are just a few examples. In other cases, support teachers will be called upon extensively in order to facilitate adaptation to and of the school.

We also have to think of other aspects of daily life. As the need arises, we can turn to the regular or specialised staff of the nursery school, or we can bring in health-care personnel or a member of the child's family, depending on what has to be done.

The teachers co-operate willingly; they have to be well-briefed and understand what is expected. When enrolling a diabetic child, for instance, we draw up what we call an individualised admission agreement, which indicates any medical requirements in accordance with the circulars of November 1991 and July 1993(Bulletin Officiel de l'Éducation Nationale, no. 3, 16 January 1992 and no. 27, 29 July 1993).

The teacher is alerted to the need for daily checks at fixed times, to nutritional and physical needs and to periods of physical effort. We cannot take exception to this when we consider that it will enable a child to grow up in his or her own, everyday environment.

Great care had to be taken in drafting this document to avoid breaching medical confidentiality; we nevertheless felt it necessary to know what the alarm signals were and the steps to be taken if a problem arose, precisely in order to forestall the risk.

## The system versus the individual

Enrolling all children in mainstream schools calls for a flexible education system. Structures cease to be predicated on the assumption that pupils must match up to an expected common standard; instead, structures are regarded as resources for the benefit of all. The crucial principle of the whole schooling process is: 'placing the child at the centre of the education system'. This phrase is particularly meaningful in the case of young pupils with special educational needs.

For each of them, an 'institution' is reinvented, and this is no chimera, even though it might appear so from the outside. The whole process is triggered by an encounter between a child, and his or her parents, and an educational establishment and its health-care partners. This notion may have something of the fabulous nature of the chimera, but it is neither an illusion nor a utopia. The aim is to set identifiable limits corresponding to the observation of the needs and abilities of the child.

Any 'institution' has a clearly-defined programme, with its aims and objectives, resources, schedule and process of 'accountability'. As the operator of a system which serves no purpose unless it produces successful learning outcomes, it is regularly evaluated: internally by the educational team responsible for its operation and compliance with mutual commitments; and externally by the special education commission acting as guarantor and responsible for regularly inspecting the ongoing integration activities.

We have, incidentally, created a new role in the implementation of integration projects; a referee, specialising in educational adaptation and integration matters, who will usually be one of the members of the network of persons providing specialist assistance for pupils in difficulty. As requested by the educational teams, these referees are not directly involved in the project, but are familiar with it. They are closely acquainted with the school environment and the teachers, and have functional links with them in addressing learning difficulties. The referee is more of an ombudsman than a supervisor and is someone to whom any of the persons involved may apply should they feel that the contract is not being respected. We have observed that children fully grasp this role.

# 2. Inclusion in a special class in the mainstream school

Another form of integration is that of the special class operating within a mainstream nursery school. Though standard practice at elementary level, this type of arrangement is less common in nursery schools. The nursery school is usually able to cater for all children in accordance with its objectives, but sometimes the decision is taken to set up specific class groups.

In the Haute-Garonne department there is a nursery class for deaf children and another for autistic children. The latter is the only one working in this way in France.

The educational mainstreaming of young autistic children began on an individual basis, but the limits of this approach were soon reached and the first class at elementary level opened in 1990. A few years later, with the benefit of our experience and of an evaluation of the admissions mechanism, run in partnership with a child psychiatric service, we started up a second class in a nursery school. Each child admitted to the class (five being the upper limit) is also cared for by the hospital unit responsible for diagnosis and therapeutic follow-up. In the class itself, a specialist teacher and a specialist health educator, both from the state system, work in tandem. Supervision is provided by a psychologist from the child psychiatric service. Parents are closely associated with the design and application of the scheme; there is daily liaison by means of a logbook, in which both parents and professionals record all significant facts, information and questions.

The school's educational team is very much involved. The young autistic children take part in all areas of collective life, including recreation and meals. They join other groups for activities matching their interests and capabilities. The teachers in charge of this type of class are appointed after an interview with a joint commission of the education and health authorities, and they then undertake to follow the necessary training.

Seeing these young children live their school lives is encouragement enough to continue working for and with them. Listening to the parents, we understand even better the significance that enrolling a child with special educational needs in a mainstream school can have for the whole family, as it begins to view and experience education like other families.

As with the other special classes operating in mainstream conditions, we had no difficulty in finding a host school for this initiative. The proposal came from a team already very much attuned to the issue, having had practical experience of individual integration.

There was also a favourable response from the local authority, which built a classroom to the specifications of the team formed by the partners. It is a specially-designed space providing facilities for highly individualised attention, rest, lessons and all the routine activities of daily life. An adjoining room with two-way mirrors enables parents and staff from the education and health ministries to engage in training without disturbing the class. This forms part of the European training scheme for those caring for autistic children.

The project is backed by France Telecom, the state telecommunication authority, through its sponsorship programme.

In France, we distinguish between children coming under the responsibility of the health sector – such as the young autistic children just mentioned and children suffering from severe chronic illnesses – 'handicapped' children coming under the medical-social sector, and children with learning difficulties. It is sometimes hard for the uninitiated to find their way around these distinctions, but the main consideration lies elsewhere. It is simply that we need these definitions in order to determine which authority, institution or ministry is responsible for funding. What really matters is the quality of the educational environment offered.

It is important to remember that the integration of a child into a mainstream school will affect not only that particular school, but also the other educational and leisure centres in the neighbourhood, such as the library and the swimming pool, which will also have to cater for children with special educational needs. On this point, while we need to be vigilant, we have no major anxieties, since the specialist institutions are also regular users and this co-operation has helped to create the knowledge and understanding necessary to provide for these children.

# SOME ISSUES FOR CONSIDERATION

# 1. The principles of integration

After three years of exchanges, subject group 2 of the European Helios programme (on the admission of young children to infant, nursery and elementary schools) drew up a list of basic principles for educational integration.

- Principle 1:
  - A value to defend and a choice for society.
- Principle 2:
   Ethical and r
  - Ethical and professional standards of all those involved.
- Principle 3:
- A choice available for parents.
- Principle 4:
  - Collaboration between all those involved.
- Principle 5:
  - Essential budgetary implications.
- Principle 6:
  - Training and recognition of teachers.
- Principle 7:
  - Only one limit: that imposed by the child.

This list can be used as a preliminary check on any integration scheme to make sure that children's rights have been respected, that the necessary resources have been found and that the educational community will be encouraged and supported in its commitment to the policy of education for all.

The integration of young children with disabilities may seem straightforward at school since social learning objectives are the most pressing. But care should be taken not to paint a false picture which is detrimental to and undermines children and their families. We realised that, while the education system was capable of addressing and coping with difference, it should have nothing to do with denying it.

#### 2. Parental choice and involvement

The choice of parents must be an informed one. We are not obsessively in favour of total integration. We work with specialist institutions which still admit severely disabled children. This is what some families choose, and sometimes it is also what the child needs.

While we, for our part, are sure that the right course is that of integration, not all attitudes have evolved as fast; not all educational partners have had the good fortune to follow or initiate successful integration projects.

We have been helped – even impelled – by parents bent on exercising their rights and playing their part in the education of their child. It was they who prompted us to be innovative and who finally enabled us to develop new solutions, obliging us to seek the necessary alliances with the health authorities. Those particular parents were resolved; other parents must be properly informed if they are to exercise their rights and responsibilities to the full.

One of the difficulties encountered is that parental demand is not always enlightened and therefore takes a lot of time to discuss and resolve – time that the child does not necessarily have. Initial demand needs strong support for the sake of close co-operation and mutual trust at a later stage.

We can inform these parents, and the parents who are already involved are able to pass on their knowledge, experience and arguments. Reflection and development are still needed if we are to devise the best means of providing the necessary information and training, which will undoubtedly entail work within a network of partners. The debate continues.

# 3. Training the teachers

Teacher training is one of the keys to success in catering for young children with special educational needs in the mainstream school.

The training programme for future teachers takes this element into account, but the time allotted allows no development of the subject and the result falls far short of requirements. There is no question of turning every teacher into a specialist in all disabilities and all learning difficulties; the aim is rather to enable each teacher to address and cope with difference for the benefit of the class group, and to be capable of practising individualised approaches and of devising and managing educational projects.

In my work with future teachers, I have noticed that the general public is deeply concerned and worried about not being able to 'cope', but seldom hostile. Interest is expressed in both theoretical and practical matters. When providing information, we should include contributions from health-care partners and interviews with parents.

#### 4. Evaluation

Another difficulty is that of validating activities. The obligation to evaluate means that suitable tools have to be developed. It seems that, at the moment, evaluation is objectives-related but we have difficulty in evaluating the processes and effects of interaction. This is a research area that will have to be taken up in co-operation with the universities.

# **CONCLUSION**

Although the ultimate aim of education for all admits to no opposition, its implementation calls for the courage to innovate and the willingness to heed the call of every child.

The integration of all children into the school system mobilises the educational, social and family environment and leads to co-operation. It benefits the entire educational community and, even if this is not its prime purpose, it provides benefits for everyone.

Integration arouses pedagogical 'curiosity' and brings about an improvement in personal performance. It encourages exchanges across frontiers and ultimately emerges in the form of demand.

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# The Integration of a Visually-Impaired Child in a Mainstream Kindergarten

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#### BACKGROUND

In Greece, pre-school education is provided by kindergartens and infant schools. Kindergartens care for children who are aged four to six and are the responsibility of the Ministry of Education. The Ministry of Health and Welfare is responsible for infant schools which are for children aged two-and-a-half to six. All the children attending kindergarten or infant school follow the National Curriculum. Children have to attend kindergarten before they can enter primary school.

Seventy-five per cent of four to six year-olds attend kindergarten. 21% of three to six year-olds attend infant school (Polyhronopoulou-Zaharogeorga, S. 1993). Parents are able to select a kindergarten but this choice is limited because the kindergartens do not operate waiting lists. In the academic year 1995-1996, 123,161 children attended state kindergartens and infant schools and 4,786 children attended private kindergartens and infant schools.

# 1. Children with special needs

There has to date been no accurate assessment of the number of children with special needs in Greece. According to international figures relating to disability, it is possible to estimate that 289,000 children between the ages of three and 19 have special needs (Polyhronopoulou-Zaharogeorga, S. 1993). The Ministry of Education information bulletin (1988) states that the total student population was 1,800,000

in 1988, including 180,000 children with special needs. According to the information bulletin issued in 1992, most students with special needs were attending mainstream schools. However, the state does not provide special programmes to assist children with special needs in gaining access to the National Curriculum.

There are five kinds of school provision in Greece for children with special needs:

- special schools
- classes in parallel
- units in mainstream schools
- · classes of children who are integrated
- centres for vocational education. (Zoniou-Sideri,1996)

The concept of integration was introduced in the Greek education system for the first time in 1974. The decision to begin the process of integrating children with special educational needs into mainstream settings did not come as a result of pressure from concerned groups of teachers or parents; rather, it was a result of legislation (Patsalis, 1994).

In 1976, the Ministry of Education assumed sole responsibility for special education, and children with special needs gained the right to attend mainstream schools (Kalantzi-Azizi, 1989). Legislation in 1981 established the integration of children with special educational needs, underlining that these children should obtain: 'equal opportunities in education, social integration and preparation for the successful transfer from school to life'.

However, it is very difficult to translate the notion of integration as written in a piece of legislation into effective practice. It is worth mentioning that even though the principle of integration was established in 1981, the number of special kindergartens actually increased during the period 1988-1989; there were 10 in 1985 and by 1989, there were 37.

# 2. The issue of integration

In Greece, we have identified a number of difficulties which have to be taken into consideration when trying to integrate children with special educational needs into mainstream education.

- Lack of a common policy regarding the advice given to parents by diagnostic centres, of which there is one in every region.
- Stereotypes and prejudices in the community.
  Research has shown that the parents of children
  who do not have special needs do not accept the
  idea of children with special needs being taught
  alongside their own children. Parents of children
  at secondary school are particularly concerned about
  this, feeling that it may impede their children's
  progress.
- There is often no physical access to the school buildings.
- Once children with special educational needs attend a special school, they are not periodically assessed for suitability for reintegration into a mainstream school.
- There are few available assessment tests.
- Teachers in mainstream schools are not trained to cope with the different teaching and learning styles appropriate for children with special needs.
- Local authorities are not interested in strategies such as early intervention and integration as they cost too much to implement.
- Support for families of children with special needs is provided by the state or private organisations. The level and nature of the support available depends on regional policies and priorities and the financial position of the authorities. It also depends on the child, the nature and degree of disability and on the parents. Financial, psychological and/or educational support may be offered. However, there is a lack of centres which provide all the services needed to support children with special needs: that is, physiotherapy; speech and language therapy; ergotherapy; psychological support; legal advice for the parents, and so on.

# THE INTEGRATION OF A VISUALLY-IMPAIRED CHILD

## 1. Aims of the programme

The basic idea of early intervention is very closely related to the theory of the 'sensitive phases' in early childhood. This theory is based on new thinking that aspects of the child's future development are 'moulded' during these phases, which therefore have a considerable influence on the child's later life (McDaniels, 1977). This realisation was an important step in understanding the value of providing stimulation for children with disabilities as early in their development as possible. There is now broad agreement amongst professionals that the earliest possible stimulation of children is a successful method for furthering a child's development and his or her integration into school and social life (Helios Report, 1996).

Taking this approach as our starting point, we began a programme of integration in an area of Athens, working in collaboration with a team of specialists. The idea was to introduce a way of achieving the early integration of children with special needs in practice; we were trying to introduce ways of implementing the legislation. It was clear that legislation promoting the educational integration of young children with disabilities is not in itself sufficient: it must be accompanied by practical approaches and examples of good practice.

The programme involved the following targets.

- 1. The integration in a mainstream school of a blind child who was selected based on her cognitive and social ability to function in an ordinary school environment. Her integration was based on the premise that a child with special needs must be considered as a 'whole person' and not just labelled and treated as a 'special need'. Children with special needs should be a main priority within the school.
- 2. The establishment of measures concerning the early intervention and integration of children with special needs in kindergarten.
- 3. Developing a quality school environment, good teaching practices and relevant materials.



- 4. The evaluation of the integration programmes, focussing on the difficulties of implementing integration strategies, and including the school's and teachers' reactions, the community's attitudes, financial considerations and the need for adequate structures.
- 5. The development of the educational policy and procedures concerning the national and local agents involved in integration (an attempt to self-evaluate these pilot programmes).

## 2. The programme in action

The visually-impaired child

The main focus of the project was the integration of a blind girl of five years old who was attending a special kindergarten. The child, whom we shall call Maria, was assessed in a number of fields such as the psychokinetic, the intellectual (language level, pre-maths) and the social. The team and the girl's

parents decided that Maria's needs could be met in a mainstream class.

The programme began in September 1994 but prior to this there was almost a year's preparatory work, involving consultation with the community, the local authority, the teachers, the parents of the non-special needs children and Maria's parents, the children in the kindergarten and Maria herself. A number of issues were discussed and key decisions taken. Most important was the selection of the kindergarten. The following points had to be considered.

- It was thought that the kindergarten should be in Maria's neighbourhood to enable her to socialise more easily with local children. Furthermore, the school could be used as a starting point for Maria in getting to know her environment.
- The choice of the kindergarten was linked to the need to find the right kindergarten teacher. A number of kindergartens in the area of Nea Smyrni were considered, looking at their proximity to Maria's house and whether there was a teacher who was interested in the programme. The kindergarten

teacher also had to be available to collaborate with the specialist teacher in assessing his or her ways of teaching and developing new approaches according to Maria's needs.

- The kindergarten had to be physically accessible.
- The lack of funding was a problem that had to be solved. The Ministry of Education funded only the specialist teacher. All other expenses were covered by the University, and the team participated voluntarily.
- A kindergarten teacher specialising in the field of special education/integration for blind children was selected.

The next step was to brief the central educational authority on the project. The basic structure and objectives of the programme were presented by the team of specialists who took part. The team consisted of a psychologist, a speech and language therapist, the specialist kindergarten teacher and a social worker.

The team's psychologist and social worker made a presentation about the project to the parents of the other children. They were given information about the child's abilities and there was discussion not only about children who have special educational needs, but also about children who come from different cultural backgrounds. Particular emphasis was placed upon this aspect of the project, since integration operates on the basis of a dynamic of assumptions. We have therefore also mobilised parents' associations, groups/associations of people with disabilities, teachers' cultural societies and so on to help us achieve a higher level of understanding and the participation of the residents.

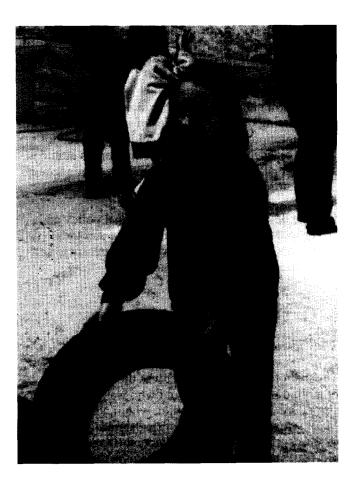
Preparation of the children at the kindergarten, through play and other activities, enabled them to understand and accept the 'difference' of the blind child. They exchanged visits with the children at the special kindergarten which Maria was attending. This strategy aimed to enable the acknowledgment of the other's individual particularity without suppressing the contradictory feelings which are often experienced when meeting a person with disabilities.

Maria was assessed and prepared for transfer to a mainstream class. During the assessment, it became obvious that she understood the 'difference' and that she was educationally and socially ready to attend the mainstream class. Simultaneously, she attended a course on Braille and a course for mobility orientation. She visited the Museum of Touch on many occasions.

She also visited the mainstream kindergarten to familiarise herself with the environment prior to her transfer. After the assessment phase the specialist teacher created the teaching material and framework necessary to give Maria access to the National Curriculum. She even prepared areas of the school in order to make Maria's movement autonomous by using the idea of multisensory environments.

Maria's parents participated as partners in the creation of the programme and its implementation.

The specialist team took an interdisciplinary approach, collaborating with the local authority and the local education authority. The team met every 15 days. At these meetings, the support teacher who was with Maria every day discussed her social and educational progress and any problems which had arisen. In this way, they worked together to assess her needs and develop new ways of working to meet those needs. They kept Maria's parents informed and offered continuous support. They also informed other members of the school and local neighbourhood about Maria's needs.



# Content of Maria's educational programme

The specialist support teacher and the kindergarten teacher included the following approaches in Maria's classroom-based activities:

- social learning creating an environment of acceptance, team acceptance, friendships, through play and educational interactions;
- intellectual development the teaching of notions. Introducing skills such as pre-number, pre-writing and pre-reading skills;
- psychokinetic area emphasis was placed on the teaching of space and autonomy;
- creative area participation in play, drama and role-play activity.

# EVALUATION OF THE PROGRAMME

The effectiveness of the programme was supported by the results of the evaluation. During the programme's implementation, a number of improvements were observed in all areas of Maria's development.

In the area of social learning, Maria was voluntarily involved in interactions with the school's staff and the children. At the beginning, she established friendships with some of the children who were interested in meeting their new classmate. Ultimately, however, she chose her friends according to her interests and needs. She even had good relationships with them outside the school environment. The child felt free and able to express her feelings in a variety of ways.

In the psychokinetic area, Maria was autonomous in her movement within the school environment; she was self-sufficient and independent.

In the intellectual domain, Maria followed the kindergarten's curriculum without difficulty; the teaching methods were adapted to her needs. The way in which Maria adapted to and accommodated the kindergarten's everyday demands on her was particularly significant. She showed an increasing desire to participate in the peer group work and a reduced interest in individual activities.

In the creative area, Maria showed an improvement in her imagination, which was developed through painting, music and drama. The activities were not designed to promote her learning in discrete areas; they were planned in a more integrated and holistic way, although assessments were made separately in each area.

The other children in the kindergarten showed a greater degree of acceptance of and empathy with children with disabilities.

This year Maria is attending the first class of a mainstream primary school and her assessment shows progress in all areas of development.

Families (both those having a child/children with special needs and those without) also benefited from their participation in the programme. During the initial phase of the project, we experienced a number of negative reactions from the parents, but according to answers given in the questionnaire which was distributed one year later, the majority felt positive rather than negative about the experience. Some of them expressed admiration for Maria's abilities.

Teachers, who were initially hesitant, gradually became involved and not only supported, but also developed, the programme. They felt that their teaching of all children had improved. The implementation of new methods of working would appear to cause anxiety and apprehension and it may be helpful to try to address this problem before such programmes are implemented.

Finally, we hope that despite the bureaucratic and financial difficulties, we succeeded in persuading the authorities in charge of the relevant institutions about the necessity of integration and its positive effects.

# When there is no Nursery School: one response to the challenge in the interior of Guyana

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# BACKGROUND INFORMATION: THE RUPUNUNI REGION OF GUYANA

The Rupununi region of Guyana is in the south west of the country and covers an area of 33,000 square miles. There are approximately 17,000 people in the region living primarily in 42 Amerindian villages and settlements which are spread throughout the Rupununi. Eighty percent of the population is classified as indigenous or Amerindian. Nearly everyone can speak English as there has been a significant missionary presence in the region since the early 1900s. Unfortunately, this exposure has also led to a great deal of cultural erosion. Many people can no longer read or write the traditional languages; the old songs, dances and arts are in danger of being forgotten.

The Rupununi region of Guyana has under-developed structural, capital, and human resources. It is the second poorest region in Guyana and has grown increasingly impoverished over time. The main industries in the region are farming and cattle ranching. Half of the land is covered by rainforest; the rest is savannah. Because the economy is subsistent and agricultural, rather than industrial, cash is limited. The problem is heightened by the lack of transport infrastructure, which increases the cost of basic goods. Unfortunately, the presence of a flourishing economy in neighbouring Brazil has led to a high level of emigration, further depleting the economic and human resources of the region.

The Rupununi region's health system also suffers as a result of the chronic underdevelopment of transportation and communication. The crude mortality rate is reported at 2.94% and infant mortality at 35/1000 live births (Geula, 1994). The Rupununi has the highest incidence of low birth weight in the country, with 41.8% of infants born below 2.5 kg. The predominant health problems of the region are malaria, diarrhoeal disease, acute respiratory infection, and accidents (Ministry of Health, 1994). The Rupununi region is the only region in Guyana where leishmaniasis, tuberculosis, and conjunctivitis present significant health problems (Ministry of Health, 1994: 35-6). Approximately 25% of children under five are immunised. In medical emergencies, patients must travel to the nearest health centre by foot, bicycle, or bullock cart, a trip which might take an average of eight to ten hours to complete.

The challenge presented by people with special needs had largely been ignored within the health sector until recently. In most villages, people with disabilities were hidden away or shunned because the indigenous folklore attributed disability to possession by evil spirits. There was a general consensus that disability was not an important issue in the region. A participatory survey carried out by the Guyana Community Based Rehabilitation (CBR) Programme in 1994, however, found that the prevalence of people identified as disabled was roughly comparable with other areas of the country: 0.76% in the Rupununi, as compared with 1.5% nation-wide.

Education in the region, though buttressed by a core of extremely dedicated teachers, is compromised both by the lack of availability in some areas of basic resources (books, paper, etc.) and by a lack of trained teachers, which leads to a system of 'trickle-down' education provided by untrained teachers. This means that the people of the region are not fulfilling their educational potential. Transportation, communication, income and climate problems all combine to make service provision in this region extremely difficult.

# PROGRAMME DESIGN AND IMPLEMENTATION

# 1. The Guyana CBR Programme

The Guyana CBR Programme views development as an organic, empowering process for the community. More traditional rehabilitation approaches are criticised for reaching only the privileged few in urban areas and for being too capital and technology-intensive, too specialised, too isolating from normal life and too Western in origin, practice, and prejudice.

The Guyana CBR Programme recognises the need to see the problems of people with disabilities in the wider context of poverty, malnutrition, ignorance, prejudice, superstition, conflict and war. All of these interrelated factors affect the quality of life of a person with disability.

CBR is based on the idea that someone from the community should be trained to design individual, simplified rehabilitation programmes for people with disabilities, which will then be run by parents or family members who have been trained to do so.

The goal of CBR is to demystify the rehabilitation process and give responsibility back to the individual, family, and community. The basic premise of CBR is that the greatest resource in developing countries for helping disabled people to lead lives which are fulfilled and productive, is a well-advised and supported family. The goal is for rehabilitation to be perceived as part of community development, whereby the community seeks to improve itself. In such a process, rehabilitation becomes one element of a broader community integration effort.

The CBR Programme is committed to a process which helps people to recognise that they can set their own development agendas.

# 2. 'Hopeful Steps'

The name of the Rupununi CBR Programme is 'Hopeful Steps in the Rupununi'. This programme evolved into an empowering process which transcends the literal definition of 'rehabilitation', affirming indigenous culture and putting control of the process of development back into the hands of the community. Thus rehabilitation is addressed in the context of wider community issues, through integration with existing infrastructure and the education of parents and community members, rather than through a top-down delivery system.

'Hopeful Steps' attempts to formulate a simplified model of rehabilitation that could deliver services to rural areas of Guyana, where the vast majority of the country's disabled people live. The programme focuses on empowering communities and community members to care for their people with disabilities and to value them as a resource, while at the same time, encouraging them to discover or reveal their special talents to their communities. Within the context of the Rupununi, the focus shifted dramatically in response to priorities identified by the people living there.

# Getting started

The CBR Programme began considering an expansion to the Rupununi region of Guyana in early 1992, even though it had concerns about the applicability of a more specialised programme in an area where basic subsistence needs governed people's lives. Brian O'Toole made an initial visit to the region in early 1992, during which he was invited to make a presentation about the national programme to a conference of Rupununi head-teachers. The headteachers' response was lukewarm: while they were interested in development efforts in general, they felt that the focus on people with disabilities would have very little relevance because, as they put it, there were no people with disabilities in the Rupununi.

The Director of the programme decided to make six one-week visits to about 20 of the 42 villages to get a sense of community needs. The response of the villagers to these visits was warm and enthusiastic; the Rupununi region had been isolated for so long that very few groups visited it and those who did rarely bothered to travel outside the one or two main administrative centres. As a result, people seemed sincerely to appreciate the effort that the CBR Programme made to get out into the Amerindian communities. The people of the Rupununi, however, identified health, transportation, and education as their most important needs. Out of this discussion, early physical and mental stimulation of children emerged as an area within

the scope of the CBR Programme which would be of considerable interest to both teachers and health workers. It was also during these visits that a training video about disability was filmed in the Rupununi.

In October 1992, the CBR Programme ran two weeklong workshops in association with the Ministry of Health. Designed for community health workers, the workshops provided basic information about early stimulation, the identification of children with disabilities and simple rehabilitation methods. The aim was to raise awareness among the health workers about these issues and provide them with the educational tools necessary to expand their capacity in this area. The first one-week event included toy-making and puppet-making workshops, a cultural show, the training video which was filmed previously in the region (see above), and adapting educational resources for early stimulation which were developed on the coast and needed to be made more relevant to Amerindian people. The participants responded to the workshop with such enthusiasm and interest that the CBR Programme met with its funders and asked to develop a long-term vision for the Rupununi region, beginning with four more workshops on early stimulation.

# The second phase: team building

For the second phase of the project, community volunteers were recruited. Teams of three, comprising the community health worker, a teacher, and a village leader, from each of 36 villages, were invited to the workshop being held in their subdistrict. Each of the participants was automatically enrolled in a three-year training programme in CBR through the University of Guyana. Many people made great sacrifices to attend the workshops; for example, some teams travelled by foot and canoe for 13 days and nights to reach the meeting.

The formation of CBR teams in each village had a number of valuable functions. It formalised partnerships between the existing education and health sectors within the village, and the inclusion of a villager in the team allowed more general issues concerning the village to be heard. Essentially, the three people in a village team began to serve as representatives of the programme at village level, thereby increasing people's awareness of the programme. Moreover, the CBR team members began to develop a sense of ownership of and identification with the programme. The selection of a team of people from each village, rather than an individual, eased the burden of work on the volunteers. A team could be seen as part of the accepted, regular system of village committees and was thereby integrated into the existing administrative infrastructure of the village. Many CBR teams were given time during monthly village meetings to report to the public and

raise awareness of the programme. As a result of all of these factors, the CBR Programme very quickly achieved name recognition, identification, and acceptance by the majority of villagers.

## The programme of action

Initially, the emphasis of the programme remained on early stimulation. The first series of subdistrict workshops focused on different ways of stimulating children through play. The workshops showed participants how to make stimulating toys out of locally-available and inexpensive materials. This component subtly affirmed the value of Amerindian resources and culture.

A second series of workshops focusing on normal and delayed child development was held in each of the subdistricts. Each workshop made special reference to the applicability of the material to children with disabilities to raise awareness of the needs of disabled people in the area. During the second series of workshops, participants' villages took part in an art competition on disability. Hundreds of children submitted entries.

The last workshop in the second series proved to be an historic one: at their own behest, one of the CBR teams brought seven people with disabilities to the conference; the workshop began by exploring what could be done to help these people. This open acknowledgment that there are people with disabilities within the Rupununi, and the way in which the CBR teams seemed prepared and even excited about dealing with the issue, now gave the CBR Programme the confidence it needed to address the issue more directly in other sub-regions.

# Focus on disability

This shift in direction was agreed by the CBR teams during a region-wide conference held in Lethem. During this conference, the participants assessed their accomplishments and made new plans for the future; these plans reflected an increasing emphasis on addressing the needs of people with disabilities.

The third CBR workshop series reflected this new focus on disability. The workshops dealt with screening, early identification of disabilities, integration of children with disabilities within the mainstream school, toy making and simple physiotherapy. A video series, called 'A New Tomorrow', highlighting disability needs specific to the Rupununi region and filmed in the Rupununi itself, was produced and shown. A storybook containing stories about people with disabilities was written and translated into the two main indigenous languages.

Over the next few months, CBR teams systematically explored the region for people with disabilities. It became clear that there are disabled people in the Rupununi who, having been hidden away all their lives, may have needs which transcend their physical or mental disability.

The process of carrying out this survey brought the CBR teams in the villages face-to-face with the magnitude of the problem within their own communities. Many began to formulate specific plans to address the needs of disabled people in their communities. As a result of this more intense focus on disability, about 20 children of school-age who had previously been kept at home started attending school.

The CBR teams began to work actively to promote the integration of people with disabilities into every aspect of village life. At health clinics, health workers began encouraging mothers to bring their children with disabilities to clinic. A number of CBR teams acted at the village education level. One CBR team made sure that every disabled person in their community was always brought to village events and meetings.

These acts of integration, which broke down age-old barriers, profoundly affected the attitudes of villagers in the Rupununi about disabled people: 60% of respondents in Stout's (1996) research sample, (N=20), identified changing attitudes towards and help for disabled people as a major impact of the CBR Programme; 35% felt that disabled people were better adapted and less shy; and 27% (N=15) identified the integration of disabled people into village life as the main strength of the programme.

The formulation of village-level plans to integrate disabled people into village life had another unexpected effect, however. Until then, the CBR teams seemed to have responded largely to programme-level suggestions; the act of initiating their own plans to respond to the needs they had documented within their own communities helped the CBR teams to begin to own the process and to identify themselves as CBR agents rather than as CBR recipients.

The CBR Programme did not however abandon its commitment to addressing broader development priorities in the region as it took advantage of the new focus on disability. At the time that the third series of workshops was being held, three other major focus areas were emerging as a result of needs expressed by villagers or identified by the programme. These three areas were: health education, literacy and cultural affirmation.

#### Heath education

The focus on health education developed as a collaboration with the Bahá'í Community Health Partnership (BCHP). A 50-minute video called 'Facts for Life', depicting the key health messages in the UNICEF document of the same name, was filmed using scenes from the Rupununi. Over the next months, CBR regional coordinators travelled throughout the region and, using portable video equipment, showed the film in each of the villages. The key messages in the 'Facts for Life' film were also summarised in a simple, pictorial pamphlet and distributed to every home in the Rupununi through village visits made by the BCHP.

A series of 'Facts for Life' festivals was held in every subdistrict and at regional level. Hundreds of poems, songs, skits, stories, and drawings were submitted to an arts competition and UNICEF funded the publication of a book featuring the winning entries. The combination of video, teaching manual, and art competition proved to be extremely effective both in communicating health messages to the general public and empowering health workers to teach these messages themselves.

#### Literacy training

Rupununi residents also identified the literacy training which developed during this same period as having a significant impact. This aspect of the programme arose out of the recognition that general education and literacy were major areas of need. There was a lack of books to read and insufficient knowledge of how to teach children to read beyond the rote repetition method. The CBR Programme devoted part of the third series of workshops to the promotion of literacy and developed a 'Steps to Reading' package. This consisted of a 15-book series, including workbooks, teachers' manuals and story books, which took teachers step-by-step through the process of promoting literacy.

# Cultural affirmation

The final area which reflected the broadening of the CBR Programme's initiatives in the Rupununi is cultural affirmation. Use of locally available materials, particularly those utilising cultural craft forms, was encouraged in the early stimulation programme. Cultural shows and art competitions were used to encourage people to translate programme themes into their own culture and environment. A book of stories around CBR themes was written and translated into Macushi and Wapishana. Several videos were filmed using people and places in the Rupununi as both consultants and active participants. All of these steps



showed respect for the culture of the Rupununi people and helped to make the programme and process culturally relevant. The programme invested a great deal of time and energy in preserving and affirming the culture of the Rupununi people for its own sake. One example of this was the production of a tape of indigenous songs and stories which are on the verge of being lost. For the people in this region, who for the last 100 years have been beaten for speaking their traditional language in school, who are seeing their culture and way of life rapidly die out with the new 'modern' generation, this work represents a badly-needed reaffirmation of the integrity and value of their culture.

The development within the Rupununi region of this broad vision of the role and purpose of CBR, which addresses the needs of people with disabilities within the context of addressing the needs of the larger community, echoes the model of CBR as part of an integrated development process, as mentioned earlier. There are many reasons why such broadness of vision

has been possible with the CBR Programme in the Rupununi, but several elements may be particularly important:

- the creation of a forum or process in which the evolving needs of people can be discussed
- the willingness of people in the Rupununi to share their perception of their needs with the programme
- the willingness of the CBR Programme to listen and respond to the needs expressed rather than to any preconceived agenda
- the supportiveness of the programme's funders

   principally, Amici di Raoul Follereau (AIFO) in
   Italy for the flexibility and broadness of the programme, which requires in turn a great deal of flexibility and broadness of vision on their part.

# **MAJOR ISSUES**

Two major challenges emerge in a project of this nature in an isolated part of the country. First, the identification and training of human resources and second, the development of an appropriate infrastructure through which to work.

# 1. Identification and training of human resources

Human resource development took place in two forms: the training of people to carry out the programme's goals and objectives, and the training of people to take over the process of development. Both of these operated at two different levels: at the grassroots, community level and at a higher, leadership level.

## Community level

Human resource development at the grassroots level took place in four different contexts:

- workshops held by the CBR Programme for CBR team members
- workshops held by CBR team members for their villages
- programme-initiated projects carried out at the village level
- projects initiated by CBR teams to be carried out within their own communities.

CBR team members learned the knowledge and skills necessary to carry out the programme's immediate objectives. For instance, for early stimulation, they learned how to make toys; for literacy, they learned how to teach phonics; for health education, they learned the key 'Facts for Life' messages.

In 1995, the CBR Programme developed a new focus: instead of simply teaching CBR workers about various topics and asking them to apply this learning in their villages, each CBR team was given the necessary skills and materials to enable workers to transmit that information on a larger scale at village level. Every CBR team was asked to organise and lead a workshop in its village about early stimulation, having had a refresher workshop on the topic. The process of organising a workshop was one which taught the participants the fundamental organisation/management skills which are needed to continue the CBR Programme in its current form. It also taught the team members how to teach others, so that they were not mere vessels of knowledge but active participants in the education process.

Programme-initiated CBR projects that were implemented at the village level also taught CBR team members the necessary skills and knowledge to run the programme at grassroots level. These efforts improved programme sustainability by increasing identification with the programme and increasing the community base of skills necessary to run it.

The CBR teams have also had an opportunity to apply what they have learned about process sustainability at a practical level, through the process of identifying community needs (independent of those suggested by the CBR Programme), designing projects and implementing them. The projects which were identified and the process of implementation varied enormously and illustrate the extent to which people were empowered by this process. Projects include:

- setting up nursery schools for children and their mothers
- upgrading or creation of health posts
- the improving of water supplies and sanitation
- establishing a sewing cooperative to sew mosquito nets.

CBR team members also had to secure funding for these projects. In several cases, the CBR Programme directly supported this process by helping the teams to locate materials or funding. However, team members mostly had to learn how to seek this funding and support themselves. This base of human resources matured even further as subdistrict and regional committees formed to carry out larger projects.

#### Leadership level

Human resource development at the leadership level took place through a 'Training of Trainers' course developed by the CBR Programme to create a group of workers who could introduce the programme to neighbouring regions of Guyana and serve as human resources within their own region. This training took the form of a one-week workshop in Georgetown. The workshop taught the diverse range of skills necessary to teach and maintain the educational outcomes of the programme, including literacy education, health education and disability identification, awareness, and management. Once they completed the workshop, these new trainers were immediately brought into the process of co-organising and co-leading workshops in their subdistrict, along with the regional and national coordinators. This provided trainers with on-going 'on-the-job' training, enabling them to practise their newly-learned skills and to develop those necessary to allow them to take over coordination of the programme.

In summary, the CBR Programme has been able to develop human resources to support both programme

and process sustainability by combining educational workshops with practical projects to enable those trained to apply, develop, and gain confidence in their new skills. A group of resource people capable of training others has been identified, trained, and is now working on the programme. As the programme has evolved and people have become more and more confident, it has been able to support participants in developing and carrying out their own projects. This has empowered people to learn the skills necessary to sustain the process of the CBR Programme. The ability of the CBR Programme to combine practical education with immediate application has been instrumental in promoting both programme and process sustainability through the development of human resources.

# 2. Development of an appropriate infrastructure

The development of human infrastructure constituted a critical component of the CBR Programme. Initially, there was just a national director and the village-level CBR teams, each containing a community health worker, teacher and villager.

Initially, village visits were made through a partnership with the Bahá'í Community Health Partnership, which already provided a mobile health service throughout the region. With the purchase of a Land Rover, the formation of what essentially became a mobile resource unit added another element to the CBR infrastructure. It also made the programme and its resources far more accessible to the people and helped the programme to understand the community better.

As the programme grew in scope and participants gained more and more power to define their own development agenda, a parallel system of planning, organisation, and administration developed which focused on initiatives coming up from the grassroots level. This system, which had its early roots in the village CBR teams, reached fruition in October 1995, which symbolically marked both the graduation of CBR team members from the IACE training programme and the election of subdistrict and regional-level CBR committees, each of which would carry out its own projects independently of the support of programme staff.

The development of this parallel infrastructure reflects a critical transfer of responsibility for the development process in the Rupununi into the hands of the community. One example of what this means in practice is the regional CBR committee's organisation of the construction, staffing and resourcing of a school in an extremely isolated village that did not have any way

of providing education for its children. The project took from October 1995 to March 1996 to complete and now 66 children are attending school for the first time in their lives. The most important aspect of this achievement lay in the fact that the CBR regional committee was able to undertake the project completely on its own. People now know how to identify a need, make plans to meet the need, and carry out the plans in an effective, empowering and unified way.

The programme staff works in partnership with the resource people trained through the 'Training the Trainers' model to run a continuing series of workshops in literacy, early stimulation etc. It is expected that these resource people will eventually be able to sustain this programme themselves within their region. They will be assisted in this process by the CBR teams.

The CBR infrastructure does not duplicate existing governmental or non-governmental infrastructure; rather, it works in partnership with other agencies. All CBR workshops in the Rupununi are carried out in partnership with the Ministries of Health and Education. These agencies periodically review the programme's plans, release teachers and health workers to participate in workshops, and sometimes co-sponsor workshops. Other NGOs also collaborate with the programme on transportation planning, and programme implementation.

CBR has become integrated into existing village, regional, and national systems of organisation. This is because CBR participants are drawn from the existing health and education infrastructure and because regional and national authorities were consulted during the planning process. The CBR team in each village is part of the village system of committees. At monthly meetings of headteachers throughout the region, CBR work is discussed as a standard part of the agenda. Reports of on-going CBR work are included in subdistrict and regional reports in health and education. It is even included in national plans in the health and education sectors. The new health plan for Guyana, articulates CBR as the centrepiece of rehabilitation care in Guyana:

'A programme objective will be to increase access to rehabilitative care by introducing Community Based Rehabilitation as the main strategy for delivering rehabilitative services at the primary care level.'
(Ministry of Health, 1994, p. 120)

This inclusion of CBR in the health and education systems adds greatly to the acceptance and sustainability of the CBR Programme at the political level.

## LESSONS LEARNED

The following points have emerged as laying the foundation for the project.

# 1. The importance of a profound faith and respect for the people of the region

A major goal of the project was to help the indigenous people of the Rupununi to bring about change in their own condition and, in the process, to take more responsibility for their own affairs. A significant element of the Rupununi programme has been the identification and training of human resources from within the region. The term 'empowerment' is now used in every article on development. Whilst the CBR workers in this region may not know the term 'empowerment', they nevertheless feel a sense of satisfaction that they are integral to the introduction of an extensive health and education programme to their own people. The goal throughout the project has been to reinforce and nurture, rather than supplant, the authority of the teachers, health workers and community leaders of the region. Education and training are at the core of the project, rather than the provision of services by some external agent from the coast. This focus has been reflected in the relative amounts of time invested by the resource people in training and development on their visits to the region.

Efforts have been invested in helping each person to recognise the role they can play in the development of their community. At the beginning of the project, the prevailing attitude of many of the participants was that they were poor, passive recipients of what others would donate to their region. The philosophy which permeated this project asks each individual to play a more active role in his or her own development and to inspire people to realise that they can indeed play a key role.

# 2. The promotion of sustainability through the avoidance of dependency

In each village a Local Health Board (LHB) has now been elected, providing a medium through which the community can be involved in all phases of the project. The goal of sustainability is the touchstone of all development interventions. Only time will tell whether this project can be sustained beyond the inputs of external interventions. However, the emergence of the CBR teams and the LHBs, and the heavy emphasis given to training these groups in the skills

of consultation, leadership, problem-solving and decision-making has established a promising base for long-term development.

Some features of the project which have promoted sustainability include:

- the clear match between regional needs and programme objectives
- the use of the existing health and education infrastructures rather than creating new groups of workers
- basing the management of the programme in the region
- the focus on involving and empowering communities.

# 3. Development which is respectful to the local culture

The project was guided by a respect for the culture of the region and an appreciation that for development to be effective it needs to proceed in harmony with the local culture. Considerable time was spent at the outset of the project to meet people throughout the region to learn about the needs of the area. One of the major activities of the first year of the project was to produce a set of training materials on child development and early stimulation, in consultation with the teachers and health workers of the region, which reflected practice in the region. These materials illustrate a profound respect for the local communities.

A diverse series of materials have been produced as part of the 'Hopeful Steps' programme. These include recordings of music and oral traditions, story books in local languages and festivals of local poetry and song, all of which reflect the rich cultural heritage of the people of the region.

# 4. Consultation

The programme brought together people from diverse backgrounds and perspectives to discuss their needs and concerns. They were given access to the decisionmaking process at every level of the intervention. Consultation with and participation by the community was facilitated at every level of the decision-making process. Facilitators listened carefully to community input and then acted on what they heard. There was no 'script' at the outset of the project: the actions of the project emerged out of the dynamic consultative process. In adopting this process we were fortunate that our funders, AIFO, realised that such a process takes time and cannot be hurried. The programme that was subsequently developed was therefore characterised by flexibility and responsiveness to suggestions from within the region.

# REPLICABILITY IN OTHER AREAS

The model of development outlined could be duplicated elsewhere, given certain conditions:

- the promoters of the initiative must have a belief in the potential of the people they are serving
- the initiators should have the ability to guide individuals, who for so long have traditionally been led by others, to take charge of their own affairs
- the active participation of the subjects of development must be achieved at all phases of the development process
- the community should have a desire for change
- the programme developers must be willing and able to listen to people who may not be articulate in the traditional sense
- the initiators should be experienced in the art of consultation
- the funders should allow those implementing the initiative sufficient time throughout the programme to facilitate the consultative process
- effective partnerships between all the key players and the major government agencies should be established.

# **CONCLUSION**

The 'Hopeful Steps' programme has attempted to develop a management style which allows the lofty concepts of 'community participation' and 'empowerment' to be nurtured. There was no predetermined script for the project; many of the most creative features of the programme emerged from the participants over the course of time. This process has resulted in a programme which has grown from a modest beginning in the area of early stimulation to a wider, integrated development programme involving many people.

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# Special Educational Needs in Early Childhood Care: An Inclusive Early Childhood Education Programme

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# BACKGROUND INFORMATION

Bangalore District is located in the south-eastern corner of Karnataka, one of the southern states of India. This district is divided into three revenue subdivisions for administrative purposes. Bangalore is also the capital city of Karnataka. According to the 1991 census, the total population of the district is four million, with children making up to 12% of the total population. A survey conducted by the Government of Karnataka in 1993 showed that six per cent of the child population (0-14 years) is in need of some special support.

India is a developing country with a predominantly agricultural base. With recent but rapid urbanisation and globalisation of the market economy, India's industrialisation has taken a giant leap.

The economy of Bangalore District is a blend of the traditional and the modern. The traditional occupations comprise agriculturally-based work such as floriculture, horticulture and so on. Sericulture, and silk weaving, are gaining momentum as an alternative source of work for rural families.

# POLICY AND POLITICAL CONTEXT

India was one of the signatories of the Declaration and Plan of Action in the 1990 World Summit for Children. This has resulted in the formulation of policies and strategies which recognise the rights of children to share in the nation's economic resources. The planning measures are initiated by the relevant government departments – such as health, primary education and welfare. The needs of children with disabilities is one of the 'special' issues on which planning is focussed.

Some of the special issues are:

- preparation of children in primary schools
- support services to girls and working children
- The Early Child Care Education plan of action has included children with disability.

The national policy for education (1986) places a special emphasis on the need to equalise educational opportunity by meeting the specific needs of those who have so far been denied equal opportunities. Outlining the steps for ensuring equal educational opportunities for disabled children, the national policy states that the objective should be to integrate those with physical and mental disabilities with the general community as equal partners, to prepare them for normal growth and enable them to face life with courage and confidence. The strategy includes the following points for action:

- Wherever it is feasible, the education of children with motor disabilities and other mild disabilities will be shared with others:
- Special schools with hostels will be provided as far as possible at district level for severely disabled children;
- Adequate arrangements will be made to provide vocational training;
- Teacher training programmes will be developed; in particular, for teachers of primary classes to deal with special difficulties;
- Voluntary effort for the education of children with disabilities will be encouraged in every possible way.

This plan of action resulted in the implementation of an integrated education scheme by the Directorate for State Education, Research and Training (DSERT), at state level. (N.K.Jangira and Sudesh Mukhopadhyay, 1987).

The plan of action was used as a basis for the preparation of the Karnataka State plan of action for children, in 1992. The plan focussed on the opening up of elementary education to everyone and the integration of disabled children by the year 2000. In 1996, a new draft plan of action was prepared by the Integrated Education for Disabled Children (IEDC) Advisory Committee which was set up by the Education Minister in 1992. The plan of action for Karnataka state on inclusive education was jointly prepared by the government and voluntary organisations.

# 1. Objectives of inclusive education in Karnataka state:

- Universal enrolment of all disabled children in mainstream schools by the year 2001.
- To prescribe a minimum level of learning, with curricular adaptations, for disabled children in mainstream schools.
- Reduction of the 'drop out' rate for disabled children in IEDC schools, both mainstream and special.
- To provide access to secondary education for disabled children, with resource support.
- To provide access to vocational training for children with intellectual disabilities both in special schools and IEDC mainstream schools.
- To focus on developing pre-service and in-service teacher training, in order to meet the special needs of disabled children in mainstream schools.
- To provide an access to education and vocational training for disabled and other deprived children, through non-formal education (NFE) programmes.
- To extend educational and vocational services for disabled adults through adult education.

The Department of State Education, Research and Training stated in 1996 that: 'To achieve the above objectives in rural Karnataka, a scheme has to be drawn-up to promote community-based rehabilitation (CBR) for all disabled persons by the year 2001'.

Comprehensive legislation was passed in 1996 by the Indian government on 'protection, equalisation of opportunities and the rights of disabled persons in India', which has emphasised the need for integrated education and community-based rehabilitation.

# 2. Recommended steps to achieve universalisation of education by promoting early child-care education: the Karnataka state model

#### Goal

Ensuring the effective participation of children up to six years of age in Early Child Care Education (ECCE).

## Strategies:

- New cost-effective designs of ECCE to be introduced in existing Integrated Child Development Scheme (ICDS) projects.
- Improvement in the quality of the programme to be assured by:
  - providing Anganwadi (pre-school) workers practical refresher training;
  - providing materials for use of trainers and the trainees;
  - providing materials for children such as picture books, picture posters and essential play materials which are replenished periodically;
  - developing the Child Development Project Officer's office into a resource centre.
- Further qualitative improvement of six ongoing ECCE programmes to be achieved by encouraging the design of low-cost, effective home-based models, and models for day-care centres and family day-care centres. Using play-centred methods will be encouraged rather than focussing on the early teaching of the 3 Rs. Pre-primary schools and classes focussing on the play-centred method of learning are to be provided with community support. Day-care centres will be strengthened through training. Goals are: adequate, safe and hygienic space; reasonable child-worker ratio; safe drinking water; supplementary nutrition; paramedic care under medical supervision; basic equipment to be provided, including linen, cradles, toys and play materials; the adequate training and supervision of workers.
- Links between ECCE and primary schools to be encouraged through interaction between Anganwadi workers and school teachers. Electronic

media support to be utilised for conveying to the parents and community the significance of ECCE. ECCE training facilities (pre-service and inservice) made available to ECCE workers and supervisors. DSERT to provide technical support and academic input.

 A suitable monitoring and evaluation system to be evolved. A unit to be established within DSERT for monitoring ECCE programmes.

# 3. Children and families of children with special needs

In India, early child care and education is provided for children between two-and-a-half and six years of age. ICDS is one of the largest pre-school infrastructures in the rural and under-developed areas, and there are 100 ICDS 'blocks' in the Bangalore district. The education department also runs pre-school programmes in the district. Besides, there are a number of privatelymanaged pre-schools called balwadi, or nursery schools. The objective of these pre-schools is mainly to prepare children for primary education and to provide nutrition and care. ICDS projects also identify and refer children with disability to mainstream schools if the child is over five years. If a child with disability is below five they are usually referred to district hospitals, as there is no government programme at village level to meet the special needs of children with disability.

Only a fraction of the children with disability receive any meaningful support through the existing programmes. The major problem faced by the rural and poor families is accessibility to the existing services.

Children with disability are not accepted in ICDS or other pre-school centres, although identification and referral is one of the components in the training of Anganwadi workers. There is also a lack of motivation on the part of the pre-school and Aganwadi teachers. The existing Aganwadi centres are primarily dealing with basic nutritional and care needs, which leaves them with very little time for early stimulation or other educational development activity. The prevalence of malnutrition, owing to poverty, requires major attention in these areas; disability is therefore not a 'priority' problem, because there are other, more pressing problems.

However there are plans to meet the pre-school educational needs within the ICDS system. Existing providers have yet to decide whether the ICDS should limit itself to identification and referral (as there is nothing much available at village level) or whether ICDS workers should be trained in inclusive education so they can meet the special educational needs within the ICDS system.

Having said this, the perception of disability as a medical problem is also preventing the establishing of village-based services to meet the pre-school educational needs of children with disabilities. It is only three or four years ago that the ICDS started looking at the pre-school educational needs of non-disabled children's care – for example, needs in nutrition and immunisation. Therefore, the ICDS must ensure that it is ready to assume new responsibilities.

# SEVA IN ACTION: THE CBR PROGRAMME

# 1. Basic organisation

Seva in Action (SIA) is a community-based rehabilitation programme, set up as an organisation, which has made an attempt to prepare the community to meet all needs of people with disabilities using existing infrastructures.

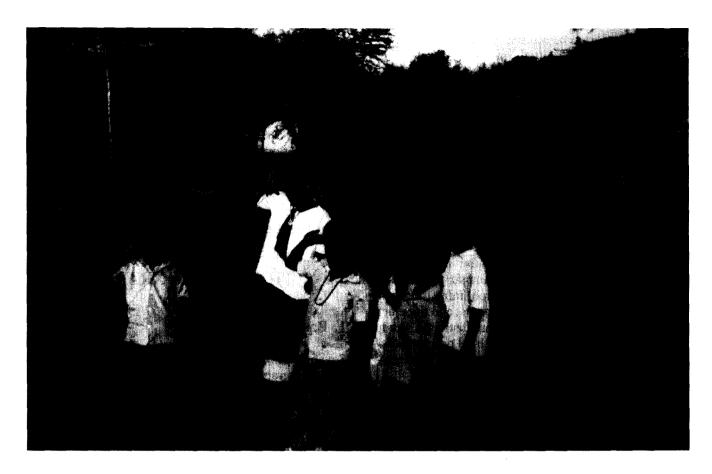
SIA was started in 1985 in Bangalore district. It has initiated village-level community-based rehabilitation (CBR) committees which are responsible for the planning and management of the programme. These committee members include people with disabilities, families, school teachers, priests and doctors, representing a cross-section of the village communities in which they are based.

SIA is supported by the Norwegian Agency for Development (NORAD), and the Government Ministry of Human Resources. However all field services are sustained by the village committees, except the integrated education support services.

The CBR committees raise funds from the local people and they support the early intervention programme. The CBR committees also fund the CBR worker's salary, medical rehabilitation and activities such as conducting awareness at local level.

# 2. Objectives

- To provide early intervention and education for disabled children through appropriate community routes, taking into account the community's sociocultural needs.
- To train mothers, Anganwadi workers and CBR workers in early intervention programmes.
- To influence government programmes by assisting in the training of personnel to provide inclusive



pre-school education. Training includes: mechanisms for the early identification and assessment of children with special needs; identification through a multi-disciplinary approach.

Early identification is the key factor for the success of inclusive education and the rehabilitation process. Identification is not a one-off event in the project; it is a continuous process, identifying disabled children in the early years of their life. SIA conducts muti-disiplinary camps for first-level identification and assessment. Professionals visit the villages, where the children with special needs are identified and an assessment is made. They are only asked to visit the district centres if they need detailed assessment.

Local CBR workers, health workers and Anganwadi workers play an important part in early identification. Regular visits to the local practitioner and referrals from the health worker also facilitate early identification. SIA has developed and tested a detailed questionnaire for the identification of children aged from birth to six years and from six to 14 years. These questionnaires can be used by local CBR volunteer Aganwadi workers and primary school teachers in a simple way. The objective of the questionnaire is to identify and categorise children with disability. Middle and high school children have also assisted in these surveys.

# 3. SIA services

- Preparation of children for integration into mainstream schools using both home-based and self-help group services.
- Integrated education in mainstream schools.
- Pre-vocational training and vocational training.
- Economic rehabilitation by using self-employed people and business – promotion of family trades.
- Community organisation.
- Appropriate aids and appliances for disabled people living in rural areas.
- Training of families and siblings.

# 4. Staffing

Trained local facilitators who are known as 'CBR Champs' are chosen by the village committees and paid by them.

These SIA local facilitators have ten years of schooling, and receive six weeks' training which includes training in Portage.

They are chosen and paid by the village CBR committees and their role is to meet the special needs of people with disabilities in their area. They visit homes to provide support for children under three years of age.

The facilitators organise multi-purpose, self-help groups which have five objectives. These are:

- helping families to care for severely disabled children
- meeting the special needs of children and preparing them for mainstream education and employment
- promoting self and group advocacy movements
- assisting families and disabled persons to help and support each other in times of crisis
- motivating the community to sustain the programme.

# 5. Human resource development

SIA conducts training programmes to develop personnel in CBR processes and trains resource teachers for integrated education programmes.

Training programmes offered by SIA

- Certificate course for teachers in Integrated Education of Disabled Children-approved course by National Council for Research and Training; duration – nine months.
- Diploma in CBR Planning and Management; duration nine months.
- Short-term courses for teachers and parents (a six-level workshop programme which enables families with disabled children to meet the needs of their disabled children and eventually helps them to form self-help advocacy movement)
- Training programmes for government education department staff at district and state level (on request from the government).

SIA also trains personnel from other developing countries in the planning and management of CBR.

# For SIA Staff

Each village CBR worker has received six weeks' training and there are refresher courses. The training programmes enable the CBR workers to plan and implement identification and early intervention programmes for the children. SIA also conducts multicategory resource training for teachers responsible for the integration of children at pre-school, primary and middle school level. This is a one-year training programme. These teachers also assist the CBR workers in monitoring the progress of children. There is training for Anganwadi workers for which SIA has developed a curriculum on the early education and care of children with disability, working to the goal of early education for these children and not just identification and referral. This training has been given to child development officers placed at taluk level (sub-division of District)

# District Institute for Education and Training (DIETs)

SIA has conducted a number of training programmes in inclusive education for personnel from the district level. Training has been supported at state and district level to prepare mainstream school teachers to meet the needs of disabled children in mainstream schools.

Teachers are also trained in the use of the UNESCO Teacher Education Resource Pack.

SIA has developed appropriate technology in CBR in the form of developing appropriate aids and appliances and education programmes for disabled children.

# STRATEGIES OF EARLY INTERVENTION AND ASSESSMENT

# 1. Early intervention

After identification there are various strategies to provide appropriate early education support where the needs of the families are given a priority. The various approaches in early intervention are:

- home-based (0-3 yrs)
- self-help groups (3-6 yrs)
- Anganwadi centres (3-6yrs)

# Home-based programmes

This service is available for children with special needs up to three years of age. The CBR worker visits homes to provide early stimulation programmes and training to parents or to the family members responsible for taking care of the child, perhaps a sibling or grandparent. This enables them to look after their children at home more effectively.

# Self-help groups

The self-help group is a multi-purpose disability centre which uses any place that is available in the villages, including temples, community halls or main-stream schools. The self-help groups meet the needs of children from three to five years of age and prepare them for primary education.

A self-help group also acts as a pre-school in villages where there are no pre-schools. It also provides pre-vocational training for children over 16 years of age.

# Curriculum used for 0-5 years

Portage is adapted to Indian rural conditions and translated into seven local languages. Both the checklist and 'how to do it' cards are available in local languages with local adaptations. Individual education plans and group educational plans are prepared by local facilitators. Recording boxes are used by illiterate parents. These boxes are multi-purpose and also used for monitoring epilepsy.

Comprehensive individual child dairies are maintained by local facilitators. These dairies have records on:

- base-line data on different aspects of development (eg: socialisation, cognition, language and communication, self-help skills, motor development) and school curriculum areas (eg: science, language, social studies, mathematics, etc).
- annual, quarterly, monthly, and weekly targets

   those set, and those achieved.
- support to families parents' training, parents' meetings, sibling support.
- preparation after school years a training package entitled *Training adults to live in the community* is used by the local facilitator.
- a six-level family training workshop programme
  which helps families to understand and meet the
  needs of their children and to get involved in
  advocacy, to find solutions to practical and serious
  problems such as 'what happens to disabled children
  when parents are no more?'

## Anganwadi centres

An Anganwadi centre is a government-run pre-school, run through the education or social welfare departments and providing children with early care and education. The objective of such centres is to provide supplementary nutrition and education. SIA also integrates children in these centres; children also have the opportunity to participate in various activities. SIA has developed a curriculum for identification and early education programmes for children integrated into these Anganwadi centres.

## 2. Assessment

Following identification, disabled children go through a process of medical and educational assessment, the main focus of which is the assessment of their strengths and weaknesses. Educational assessment is conducted in the resource centres attached to main-stream schools or in self-help centres. Parents play an important role in the assessment of their child. Informal assessment is done by the parents who list

the strengths and weaknesses of the child according to their knowledge and experience. The teacher also undertakes an informal observation, which takes between a week and 15 days. Following the informal assessment there is a formal assessment, based on the adapted version of the Portage check, which is translated into the local language. This is a criterion-referenced checklist used by SIA for both assessment and planning purposes. This checklist is able to assess the child in the following areas:

- language development
- · motor development
- socialisation
- · self-help skills
- cognitive development.

This is recorded in a home-school dairy which is maintained for each child.

# PLANNING AND MANAGEMENT

# 1. Planning

There is comprehensive planning, based on the identified strengths and weaknesses of the child. This planning is done for a full year, which is then task-analysed into quarterly, and, finally, weekly plans. The planning is based on the adapted version of the Portage checklist and curriculum for pre-vocational training. An individual education plan is drawn up for children with particular moderate and severe difficulties, and those with problems in areas as cognition and language. Group Educational Planning is more common, as it is a more effective use of local facilitators' time. Although the teaching is in small group settings, the evaluation and assessment are always carried out on a one-to-one basis.

Local facilitators are trained to choose targets relevant to the families and village community, and this has helped to increase acceptance of education for children with special needs.

Behaviour modification techniques are used with all disabled children. These children are prepared for integration into mainstream schools. If they are not eligible for integration, perhaps if they have moderate or severe learning difficulties, then they are prepared for vocational training.

# 2. Monitoring mechanisms

# Overall programme monitoring

Village level committee " æææææÆ Director

Ø
Field coordinators

Ø
Multi-purpose resource teachers

Ø
Local facilitators (CBR Workers)

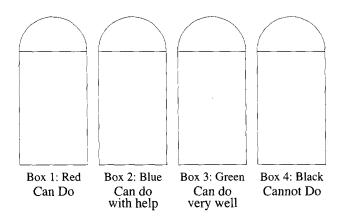
## Monitoring of self-help groups

Once the individual and group education plans have been written, the CBR workers monitor their implementation on a daily basis, using the targets and additional information from the individual diaries to measure outcomes. There are monthly monitoring meetings of the local committee and additional monthly reporting by the field coordinator. The monitoring records and staircase developed by Dr Helander, from the WHO Manual, are the main instruments used.

# Home-based monitoring

Recording boxes for illiterate families.

Besides diaries, there are recording boxes maintained by the parents if they are the teachers at home. This ensures daily monitoring of targets planned.



How to use recording boxes: trainers drop a pebble or a stone for different responses. CBR workers count them once a week and record them in the diary. The boxes are also used for epilepsy monitoring, as it is difficult to get information as to whether medicines are being given regularly.

#### Local CBR Committees

Local committees are formed at the community level which are ultimately responsible for sustaining the CBR programmes. These committees are also equipped to monitor all the services of SIA. The monitoring is done through a standard proforma which they complete and send to SIA once a month. There is also a central meeting of all the committees to discuss the problems and issues faced in implementing the programmes.

# 3. Links with specialists/support system/ referral system

Education is the only service which is available in every Indian village. No other support system for rehabilitation exists in rural areas. The SIA emphasis has been on the demystification of rehabilitation technology in order to make it accessible, appropriate, affordable and relevant to rural areas. Eighty per cent of rehabilitation services are available in the villages; in the field of education, 100% support is available from the CBR system at community level.

# **PARTNERSHIPS**

# 1. Parents

As far as caring is concerned the Indian family, with its closely-knit structure, provides a caring environment for the majority of its children. Thus SIA has been able to utilize this strength and has made self-help groups a forum to bring families together in planning and managing the programmes. The family members are members of the local CBR committees which are responsible for running the programmes at community level. The parents have been trained to manage their disabled child at home. They are also responsible for providing a monitoring support to the CBR teacher.

# 2. The community

CBR builds on the strengths and potential inherent in the community. CBR committees are the backbone of SIA's programme. There are eleven CBR committees in the rural areas of Bangalore District. These committees have been formed over a period of time by local people from a variety of backgrounds: teachers, doctors, principals of schools, social workers, agriculturists, members of women's organisations, and also parents of disabled people. These committees have come together and are bound by a common social concern for and social accountability to children with disability.

The major responsibility of the community is to mobilise resources and to plan and implement the programmes at the community level. The community is also being prepared to monitor the rehabilitation services so that there is less dependency on professional and district input. Each CBR committee would meet once a fortnight to review the services of the monthly village committees.

# PROBLEMS AND MAJOR ISSUES

The communities have played an extremely important role in sustaining the SIA programme. During 10 years of SIA programme activity, there has been a considerable change in attitudes towards disability.

Some of the major problems faced by SIA are:

- sub-standard government schools
- a less than positive attitude from policy makers towards the education of disabled children
- prescriptive curriculum in primary schools and compulsory levelling of all children
- special education is still planned on the basis of labelling children according to disability, rather than being based on levels of ability
- disabled children are scattered throughout rural and tribal areas
- access, whether physical, educational or social, is a limiting factor in promoting inclusive education
- a complex association between poverty and disability, where we find mothers are over-burdened with field work/house work/the demands of bringing up a disabled child

Single-teacher schools are generally viewed as a negative factor for integrated education, but SIA sees them as a plus point as they allow mixed ability level learning.

A classroom for all is still a dream which is yet to be achieved in Indian village schools.

# Specific problems

#### Parental attitudes

The head of the family, who is also male, has a dominating role in the family and society. Therefore, the attitude of the father towards the child influences the attitudes and actions of other members of the family too.

The basic issue for the parents and the community is time. The majority of the parents are dependent on agriculture and self-employment, and each and every minute is crucial in sustaining their livelihood and meeting their basic needs. Therefore, they are not able to give time to their child and parents' responsibilities, meetings and so on.

# The attitude of the Anganwadi teachers

Although a policy decision has been taken to promote inclusive early childhood education, the priority is still taking care of the basic needs, like nutrition. Education is still not always seen as a priority for the children.

Availability of trained personnel at middle level management

Monitoring of programmes by trained personnel is one of the major factors in sustaining quality. It is seen as a necessary evil to maintain the quality of services.

# LESSONS LEARNT

- Disabled children need trained community workers to meet early intervention needs.
- Early intervention programmes cannot be sustained unless the families are active partners.
- The best possible support should be available at village level 90% of special educational needs should be met at community level.
- Integrated education should be seen as a way in to improving existing primary education. Inclusive schools, with an inclusive curriculum, provide a cost-effective education.
- In Karnataka state, the government has set an advisory committee for IEDC. This committee has played a major role in bringing about policy changes, introducing integrated disability contact in mainstream teacher training programmes, and setting up an ICDS workers' training programme. Action groups on IEDC at state level are necessary to promote IED in developing countries.
- In CBR, people have the misconception that there is no need to look at special educational needs. It is important that the CBR programme should see IED as an integral component, as 80% of the needs of children with disabilities are educational rather than medical.

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# LAO PEOPLE'S DEMOCRATIC REPUBLIC

# Experiences in Provision for Children with Disabilities using the Kindergarten Sector

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'DON'T USE MATURE WOOD IF YOU WANT TO BEND IT; DON'T PICK OLD MUSHROOMS IF YOU WANT TO EAT THEM' (Lao proverb)

# INTRODUCTION

In 1992, in a cooperative venture with the Lao Ministry of Education (MoE), the National Centre for Medical Rehabilitation in the capital city of Vientiane opened a small school for children with sensory impairments. In all, 27 deaf children and 10 blind children enrolled. The centre was staffed by retrained physiotherapists. This was the first ever special education available in the country.

One year later, Sapanthong Primary School in Vientiane became the first Lao primary school to be able to cater for the needs of children with disabilities. In 1995, six more primary schools and four kindergartens were included and in September 1996, a further six kindergartens and seven primary schools opened their doors to children with disabilities, bringing the total to 25. This pilot project unites three distinct but related concepts - school improvement, education for all and early intervention.

# **BACKGROUND**

#### Laos: the country

Eight years ago, no thought was given to the needs of children with disabilities when the government of the Lao People's Democratic Republic (PDR) began the process of school improvement. Rather, school improvement was a response to the particular difficulties of quality and access to basic education faced by the Lao Education service at that time.

Laos is a small and very beautiful country in southeast Asia. Except for the plain bordering the southern reaches of the Mekong River it is largely mountainous and forested. It shares borders with China, Vietnam, Cambodia, Thailand and Myanmar. It has one of the lowest population densities in Asia (19 per square kilometre) and a total population estimated at 4.5 million in 1993. This population is scattered and ethnically diverse with between 38 and 68 different ethnic groups (depending on the definition used), many of which speak languages other than the national Lao

# Box 1

## THREE FACTORS

## School improvement

'School improvement may be the result of the introduction of integrated education, or provide the opportunity for integrated education to happen, but whichever route is taken, school improvement must take place'

Towards Inclusion: SCF(UK)'s Experience in Integrated Education, 1995

# Education for all

'Create conditions for the handicapped children who are willing to study and give them a chance to study in integrated classes with non-handicapped children.'

Art 13: Policy on Compulsory Education; Lao PDR 1996

## Early intervention

'The pre-school is the strong central post round which the house of primary education is built. If we compare the children who have had access to pre-school with those who did not, we can see very clearly how well they do later on. Integration is so beneficial for young children [with special needs]. It helps the children to overcome their difficulties, to be independent; it prevents isolation and gives them access to a social life'

MONE KHEUAPHAPHORN, Director, Dong Dok Kindergarten, September 1996

language. These are generally linked into 3 broad groups: the majority, 55%, are Lao Loum (lowland people); 27% are Lao Theung (midland people) and 18% are Lao Soung (highland people).

Laos has rich natural resources in its many rivers and forests which are largely undeveloped, although electricity is being produced and hardwood harvested. Further forest is lost annually through slash and burn farming methods in the mountains. Indicators show that Laos remains the poorest country in the region, with 85% of the population relying on subsistence agriculture supplemented by hunting, fishing and food gathering in the forests (Asian Development Bank: 1993). In the last 10 years, there has been some manufacturing and light industry development, but only in the lowland areas where the necessary infrastructure exists.

Prior to the 1975 revolution, Laos had experienced 50 years of colonial rule and 30 years of uninterrupted civil war, culminating in devastation from American bombing in the period 1965-75. The new Lao People's Democratic Republic was faced with formidable tasks: 800,000 displaced people; little infrastructure; insignificant financial resources; a serious lack of skilled personnel, as many of the educated elite had fled; a post-war withdrawal of American aid; and a trade embargo from its most easily-reached neighbour, Thailand (UNICEF Children and Women in Lao PDR: 1992).

# The education system

In the last twenty years, remarkable progress has been made, particularly since 1986 with the adoption of the New Economic Mechanism and the related Public Investment Programme with its emphasis on the need for skilled personnel to fuel economic and social development. In 1975, fewer than 30% of Lao children had access to primary education. By 1990 this had risen dramatically with the enrolment of 85% of urban children, 72% of children in non-mountainous rural areas and 38% of children in the remoter mountainous areas (Lao PDR MoE: 1990). Geography, ethnicity and gender continue to affect enrolment rates, with Lao Soung girls in the mountains least likely to be in school.

It is acknowledged, however, that this increased access was not matched by an improvement in quality. Schools are still often rudimentary and may lack materials, teaching aids and books. Many teachers lack any training and may even have received only a primary education themselves. With very low pay, most teachers have to supplement their income with second jobs or by growing food. Teaching methods have relied on rote learning and are based on an outmoded curriculum which relates little to the lives of the children. The repeater and drop-out rates have consequently been very high. In 1990, it took an average of 13 years for children to complete primary school and fewer than half of enrolled children achieved this (Lao PDR MoE: 1990).

#### LAO PEOPLE'S DEMOCRATIC REPUBLIC

Following the five-year primary programme, some children move through to a three-year junior high school programme and then a three-year senior high school programme or vocational training course, although access is limited.

Higher education is available at a university or polytechnic. Teacher training for the primary and preschool sectors is offered in various forms - for instance a three-year course following junior high school (8+3 system) and a one-year course following senior high school (11+1 system).

After the revolution, the pre-school sector was very rapidly developed, primarily to enable Lao women to work and thus achieve greater equality. Many kindergartens (3-6 years) and nurseries (3 months to 3 years) were attached to the workplace. Kindergartens were nevertheless seen as places of education, although the quality was poor, often reproducing the formal teaching methods of the primary school.

Lao culture is warm and accepting. Children have never been arbitrarily turned away from school because of some perceived deficiency, but neither has a school felt a responsibility to teach such children. If parents thought their child should be in school and could get them there, they were enrolled in grade 1. But for those children who needed more than the rote learning, formal system on offer, failure, repetition and repeated failure inevitably led to withdrawal at some stage. Children with clear and obvious disabilities faced greater problems. If, for instance, it is going to take weeks of patient teaching for a child to learn a simple skill, and if parents have no concept of what might be possible or have never come across another

child 'like ours' who has learned, small wonder that the sensible response is to feed and care for the child and accept the inevitable: nothing can be done. This is the same response as that of a teacher who accepts, without question, that many children will fail and assumes their own actions cannot change this situation.

# SCHOOL IMPROVEMENT

## Development of a new programme

In 1989, as well as continuing to work on the issue of access, plans were laid to start the process of quality improvement through addressing teacher education and the curriculum. The government sought various partners, including Save the Children Fund (SCF) UK which helped with the pre- and in-service teacher training programmes in both pre-school and primary sectors, and with the introduction of more childcentered teaching methods in schools. This work led to the development of the current integration programme. The interaction between the various elements of the improvement programme can be seen in Box 2 below.

The issue of teaching methodology (how best to promote learning within the school) grew through the consideration of the curriculum (what to teach) and how best to prepare teachers for the job (what teacher trainees should learn and where they can best learn

DEVELOPMENT OF INTEGRATED EDUCATION (IE) PROGRAMMES IN THE CONTEXT OF SCHOOL IMPROVEMENT

1990
1993
1995
1997

Primary Curriculum and Teacher Training Reform

SCHOOL IMPROVEMENT CONTINUUM
Project

Pre-school Curriculum and Teacher Training Reform

the necessary skills). One report on the changes taking place in the primary sector was entitled 'Learning to See' and for those involved this was certainly the key to the introduction of new methodology. Key questions were: what is happening in the classroom? Why do so many children fail? How can we teach in ways that limit failure and enhance learning within our limited resources? A variety of strategies were employed, including:

- the adoption of more child-centred active teaching approaches
- the use of home made visual aids
- greater involvement of children
- better interaction in the classroom
- a wider variety of activities
- · more and better planning and recording
- · on-going assessment
- above all, a new attitude in which children's differences were acknowledged and teachers took responsibility for the learning going on in the classroom.

It was this process that highlighted the clear needs of those children who had failed to learn and the need to consider the issue of those children whose parents did not enrol them at all.

Pre-schools do not, as a rule, 'fail' children and make them repeat grades, and so the introduction of a play-based curriculum and active teaching did not immediately highlight children with learning problems. Nor is pre-school compulsory, so the fact some children were 'missing' was never an issue. Nevertheless, the growth in thinking about the development of the child and giving attention to the whole child helped pre-school teachers become aware of differences in children. The changes brought about were far reaching (see Box 3). Furthermore, once integration had started in the primary school sector it became very clear what pre-school could offer children with disabilities.

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#### Rox 3

# KINDERGARTEN IMPROVEMENT

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Before improvement.

'The teaching was based on an old curriculum and conducted subject by subject with the teacher at the centre of the process. Teachers did a lot of talking and the children could only be listeners; they had very little chance to participate. The teaching and learning outcomes were not satisfactory because the teachers dominated the whole classroom. Teaching aids and toys were not usually available and, if there were any, they didn't relate to the topic and weren't attractive to children. There was some indoor and outdoor play for them, but it wasn't well organised. The activities were controlled by teachers and the children had no access to free play or choice. During class time all the children sat on the benches and listened carefully to the teacher's instructions. Assessment of teaching and learning was poor because there was a low understanding of children's psychology – the teaching and recording was not in sequence'.

#### After

With the [improvement] project new teaching methodologies came in which helped the teachers develop their knowledge, their concepts and their practical work. This was continued with the introduction of the new kindergarten curriculum. The methodology had changed from putting the teacher at the centre, to putting the students at the centre because it is based on an understanding of four aspects of child development (physical, mental, emotional and social) and the need to develop child participation in the teaching and learning process. The philosophy is 'learning through play' which includes many activities. Teachers use a variety of methods and teaching aids and organise and decorate the class-room according to the teaching topic. During play times teachers take the lead at first and then allow free play both indoors and outdoors. To sum up: the new way of teaching helps children become happy, healthy and creative. Since the implementation there have been regular whole school meetings and monthly classroom meetings with parents so as to ensure parents can support their children's learning and also contribute to the school when it is needed. Parents are happy to see their children's skills and behaviour change and that the school has become an attractive place for children.'

Mone Kheuaphaphorn, Director Dong Dok Kindergarten, September 1996

#### LAO PEOPLE'S DEMOCRATIC REPUBLIC

# Main elements of the school improvement programme

The main elements of the pre-school improvement programme include

- the study and understanding of the development of Lao children across four aspects of development: physical, mental, emotional and social. This is not a one-off 'external' study, but an active engagement of teachers and teacher trainers. In 1995, the kindergarten sector produced the first Lao book on child development and assessment which was based on this growing body of knowledge. This is the first time it has been possible to see clearly which children might be falling behind and so need additional help. This work continues with growing understanding of the cultural differences within the population;
- planning, recording and assessment procedures based on child development;
- play and activities as a basis for the pre-school programme;
- use of all the senses to reach children concrete things for children to touch, smell, explore, sense and feel so that the balance between the modalities is changed from the over-dependence on listening;
- variety of group size, particularly the use of 'circle' (small group) sessions;
- attention to the environment so that the school is both safe for children and attractive – this includes decorating the classroom, the use of interest corners and play corners;
- very flexible use of the indoor and outdoor space
   children use tables for some activities, sit on the floor for others, work or play under a tree etc.:
- the build up of teaching aids and play equipment made by teachers from available materials – both natural (of which there is an abundance) and junk which is now becoming more available in cities and small towns;
- much greater use of the oral culture which surrounds the children – stories, poems, songs and dances;
- building strong interactive relationships with children by ensuring that teachers and children are in close contact. As the teacher moves away from the blackboard at the front to engage in the activities she has set up, interaction increases;
- seeking the highest level of involvement from children as possible, so that children are busy and active;
- creating new types of sharing partnerships with the families so that their role is not just to deliver children at school and provide a little extra money; rather, they are engaged together with the teachers, in the learning and development of their children;
- strengthening the management of the school so that it can, from small beginnings, develop and improve the education and care of the children.

# Implementing the programme

These changes were first introduced by the 'demonstration' kindergarten attached to the teacher training institute, which enabled the new pre-service training to include practical skills training for the students. It also provided administrators and teacher trainers with an experimental classroom situation within which they could devise the programme and in-service training that would be needed. This in-service training continues through regional and provincial centres, actively encouraging and supporting new young teachers to hand on their knowledge from the new course. The programme enlists the help of teacher trainers and head teachers to support and monitor change, produce training material, train regional trainers and help in the setting up of administrative systems.

All this has been accomplished with relatively modest budgets. Since 1990, costs have included:

- enabling learning from outside through study tours and visits for the team of MoE administrators, teacher trainers and head teachers
- giving access to written material and research, including translation costs
- funding an external adviser for two years to support the team's learning and planning
- funding the production of new study materials for teachers and students
- funding short in-service training courses at various levels.

Working in this way, Lao educationalists have been able to use relevant international research and experiences when trying to find ways forward which are consistent with Lao culture, needs and opportunities. The process has been quite different from the importation and imposition of external models that can result from short-term consultancies.

One very important side effect of this way of working has been the establishing of a group of educationalists able to devise, plan and implement change and development. This group is now contributing to the development of new directions in village family support which are currently being piloted and, as discussed further on in this paper, are key personnel in the introduction of integration.

## **EDUCATION FOR ALL**

#### A statement of commitment

It is not surprising that a country which has made such an effort to improve access to primary education should be strongly committed to the concept of 'education for all'. The Lao government is a signatory to the Salamanca statement on 'Education for All' (1994), the Convention on Child Rights (1991) and its recently adopted decree on compulsory education (1996), together with the plan of action to enable this to be achieved. This commitment includes disabled children. Currently, Laos is assessing the needs of small, multi-grade schools in isolated villages, considering the particular situation faced by girls and the problem of providing suitable education in the complex cultural and linguistic environment which prevails.

The twin forces leading to the development of integration have been the experiences gained through the primary school improvement programme and the involvement in the UNESCO initiative, including attendance at the regional seminar (1993, Harbin, China). Following this, a project board was set up by the MoE and the National Rehabilitation Centre to devise an exploratory, pilot project. They were able to secure funding from UNESCO for an in-country workshop and to use regionally available expertise from SCF(UK), which also provided the necessary financial resources for the programme. This was later supplemented with additional funds from UNICEF. Outside expertise was necessary as their were no Lao professionals with training or experience in this field. Countries with an established special school system may not need to import expertise in this way.

### The pilot project

The primary school chosen for the pilot project was one in which the school improvement process was well established. There was felt to be a committed staff and good leadership in the school and there were already three children with clear special educational needs on roll. In-service training based on the UNESCO 'Special needs in the classroom' pack was provided to deepen the understanding of new methods and prepare the school and the local community for admission to the school of children with special needs. During the first academic year (1993/94), twelve children were enrolled, mostly in the lower grades, and weekend in-service training continued throughout the year. The following year there were 17 children, including those who had been in school

(and failing) and whose learning problems were at last being recognised and acknowledged.

This pilot phase provided an important learning experience and in the first half of 1995, the project board deliberated on what had been learnt and what the next step might be. It could be seen that:

- the inclusion of children with special needs was possible in Lao primary schools provided that the teaching and learning was active, interactive, and flexible and that teachers were supported through in-service training and ongoing support systems;
- introducing integration could deepen and speed the school improvement process by highlighting the difficulties children might encounter in the classroom and providing methodologies for helping many children when they faced temporary or long term problems, thus reducing the failure and repetition rates throughout the school;
- while the general introduction of improved teaching methodology was the basis for the integration programme, teachers also needed to know what kinds of difficulties children may face and to have access to ways of overcoming these. They also needed problem-solving strategies for when they were faced with unfamiliar situations presented by the diversity of the children;
- changes in school regulations regarding assessment and progression were needed;
- it was intended that inclusion should become standard practice for primary schools (thus achieving the goal of education for all), but the level of training and support that the pilot school had received could not be made available to the other schools. The process of change would need to be quick and cheap, and the training and leadership team would need to be expanded;
- teachers had found it quite difficult to accomplish integration successfully and it was realised that the major difficulties could, and should, be eased for any new schools. It should be recognised that both teachers and schools need time to develop skills and that asking too much early on only created anxiety and dependence on the training and support team. Looking at the pilot school it could be seen that a number of factors had caused the most difficulties, most of which are related, not to the ongoing situation, but to the previous period when there were no services. Demand grew so quickly that children outside the schools' normal catchment area were being enrolled. The four main factors which caused problems were:
  - i) the recruitment of older children (10+) whose long-term exclusion had resulted in low social skills and subsequent behaviour problems;
  - ii) the recruitment of some children with severe learning difficulties;

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iii) over-recruitment, so that some classes contained more than two children with special needs which distorted the teaching/learning environment and placed too much of a burden on teachers; iv) using the old curriculum (the new curriculum was being brought in one year at a time, ie. for grade 1 in 1994, grade 2 in 1995, grade 3 in 1996 etc.)

In considering these issues and formulating the next step, the project board felt that introducing early intervention for children with special needs could be advantageous.

## **EARLY INTERVENTION**

### The rationale

There is clear evidence that early intervention can be very beneficial for children with special needs. When early intervention is available, children do not suffer the additional problems caused by social isolation, and the lack of stimulation and training which arises from distress, low aspirations and a low level of understanding in many families. During the kindergarten period, with its emphasis on and understanding of the all-round development of the child, special attention can be paid to the child's needs. Families can get a more realistic picture of their child's potential and

reach a better understanding of their role in helping to realise that potential. Furthermore, there are no problems with discrimination by other children at this age; the child will grow up with his or her peers and they can continue together through the primary school with the more able children supporting and helping their friends.

In Laos, a small, but effective, kindergarten system was available. It was felt that such kindergartens, with their understanding of child development, improved methodology, positive attitude to parents and strong emphasis on social development could provide, for at least some children, a strong start. In addition, it would be possible to recruit to the team an additional layer of trainers and support personnel who would bring with them the skills and understanding of child development which could help teachers, particularly primary school teachers, to assess children and plan learning programmes. Whilst it would never be possible for all children to benefit from kindergarten, a significant number could, and the development of primary integration could be speeded by working through the kindergarten system.

## A national implementation strategy: the pilot

Expansion was planned within the Vientiane municipality (three kindergartens and five primary schools) and the southern province of Savannakhet (one kindergarten and one primary school) so that a possible system could be tried out. It was largely based in



Vientiane so that the Vientiane-based implementation team could monitor the situation closely in the first year. On the other hand, a pilot outside Vientiane was also needed, so a modest start was made in Savannakhet.

It was decided that a sustainable and expandable programme would need to ensure that the continued development of the schools was in the hands of local administrators and individual schools. This would keep support from the central implementation team (now expanded to include administrators and technical staff from the MoE, teacher trainers and head teachers from both sectors and the rehabilitation centre staff) to the minimum. It was not financially possible to employ visiting resource teachers or other forms of support staff outside the general system, either for the pilot or an expanded programme. Continued support for this work had to come from experienced teachers, head teachers and administrative staff in local areas. Therefore, developing the process and habit of discussion, sharing and joint problem-solving was a key factor for success and it was important to develop this from the start.

It was also felt that initial training should be kept as short as possible so that it would not become overtheoretical. It was impossible to provide practical experience before starting, so training opportunities were split, with more training given after work had

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started, thus enabling teachers to draw on their initial experiences of the project. As it was felt that kindergartens had valuable insights into working with families and in understanding child development, the unusual step of training teachers from both sectors together was taken.

The project board and implementation team carried out the following workplan for the academic year 1995/96 for the ten new schools, using Sapanthong school as a resource.

## Workplan

- five day-long workshops, firstly for local administrators and head teachers and then for deputy head teachers, grade 1 and 2 teachers and at least two teachers per kindergarten, with the head teachers acting as group leaders
- recruitment of a maximum of two age-appropriate children per class into lower grades and the targeting of all other children in the school with a history of failure;
- ongoing support including staff meetings and discussions, support from local administrators, assessment visits from Rehabilitation Centre staff and visits from members of the implementation team;

## $\mathbf{Box}.\mathbf{4}_{(i,j)}$

## SOME OF THE CHILDREN

Sonthong has Down's syndrome and on admission to the kindergarten in October 1995, aged 5, he spent much of the day on the floor. He took no part in any activities and seemed to have little awareness of what was going on. He could not feed himself or go to the toilet alone. By June, he was fully integrated in the class and took part with his classmates in the demonstration of morning exercises for parents on 'children's' day'. This entailed a long series of quite complicated movements and the singing of the national anthem in which he joined with enthusiasm. Of all the people there, perhaps only his mother and his teachers were really aware of what he (and they) had accomplished.

Pousey was three when she came to school. Brought up by her grandmother, she had spent her days indoors. With physical problems affecting her lower legs and right hand she crawled around the classroom and was frightened of the other children. With advice from the rehabilitation centre, the teachers set to work. Within weeks she was feeding herself and one year on she has just started to walk and is using both hands, although not equally. She is very bright and joins in all activities. Her future is assured.

Vilayvanh is nearly 4 years old and has learning problems. Frightened and isolated, he spent the first few weeks in kindergarten clinging first to a blanket and then a carrier bag full of other bags. Gradually he began to take part more and more in what was going on and now seems a full member of the class. He still has his bags but is able to put them on one side for periods and can even joke about them with the teachers. This year he moves into the top kindergarten class so as to prepare him for entry into an (integrated) primary school in one year.

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- occasional extra training for any school showing difficulty – such as allowing a delegation of staff to spend some time with a stronger school;
- a mid-year seminar which included some parents and other members of local communities, during which each of the Vientiane schools hosted visits from seminar participants;
- encouragement to develop ongoing relationships between schools;
- workshops for some grade 3, 4 and 5 teachers and more kindergarten teachers at the end of the school year.

### **Results and evaluation**

Results have been generally good. Seventy-five children in all have been included and the only real problems were where school improvement had not progressed sufficiently or where pressure (and the very real difficulty of refusing places) led to a primary school taking on too much and overloading some classes which then were unable to complete the year's curriculum.

One pleasing result, unlooked for in this first year, has been the drop in the failure and repetition rate in many primary schools. As one head teacher said: '1995 was the very last year of high repetition rates. We can now recognise difficulties long before the exam and put in extra help.' In her school, the grade examination failure rate had dropped by over half, and all but one of the 10 children with special needs were moving up a grade in September 1996.

Work in the kindergartens has gone very well, with all the recruited children showing significant improvement, including those described above. It takes little imagination to consider what the situation for each of these children would have been, had education only been offered to them at the age of seven.

Kindergarten staff immediately recognise the relationship between school improvement and integrated education and see the new tasks as deepening their general teaching skills. They are better able to see individual difference and the need for the all-round development of the child. They have also seen how much co-operative working relationships can contribute to the work of the school. This aspect of the programme is therefore very welcomed and seen as an additional spur to general school improvement.

Kindergarten teachers have also been very pleased that their special skills in working with families in social and emotional development and creating interactive relationships with children have been recognised, and that primary school teachers have come to see how



those same skills can enhance their work. Kindergarten teachers often have lower status than other teachers — 'they only look after little children'. This is as true in Laos as it is elsewhere. Co-operation and joint training is leading to a reassessment of their skills and roles. When primary school teachers turn to them for ways of improving children's social skills, for ways of involving families, for methods of making teaching aids and for their understanding of child development, their self-esteem and confidence grows.

Families and communities have very much welcomed the programme. Previously, when no services were available, families were isolated and, feeling that there was no way forward, were unable to help their children. With access to school and a personal relationship with the teacher, attitudes have quickly changed and many families are working hard alongside their children. Seeing the changes in the children and their families, communities have become very supportive, and as these children have never been removed from the village or urban district into institutions, there is no feeling that they should be 'somewhere else'.

All teachers have made very full use of the mutual support which has been encouraged and indeed this would appear to have been one of the key components of the programme. This has been seen to be true elsewhere in school improvement work (e.g. in the UK) but where there is very little expertise to call on, where there are no diagnostic and assessment procedures for young children and where there are, as yet, very few reference materials, teachers have to work together, learning how to observe, discuss, plan, and evaluate results themselves. This can only be done through a co-operative team approach within and between schools.

It is also clear that the high level of co-operation between everyone else involved is vital. This includes co-operation at ministry and policy-making level, especially between health and education, between administration staff across and within levels, between schools in different sectors and regions, between teachers, between schools and families and the community. This co-operation is based on an acknowledgment of the rights of disabled children to have a full part in society.

Teachers acknowledge the additional work involved, but also understand the foundation they are laying down for the children in guaranteeing their rights and their contribution to society. Furthermore, the large and small successes that they have achieved are creating a more confident and enthusiastic workforce. As one person said: 'Sometimes we can't explain what has happened because we are so thrilled at what we have done.'

## The next steps

With word spreading, one current problem is the enormous demand for expansion. For example, in one district with one integrated primary school, requests were received from all the adjacent villages' primary schools. It would be very easy to overwhelm the implementation team, which would mean that schools would not receive the necessary support. One of the strengths of the team is their day-to-day work in different branches of education, but work on this programme is still new to team members and must be fitted into their other responsibilities. One way of addressing this problem is to expand the team gradually from those schools with experience of integration. Already some head teachers are beginning to take on this additional role. Nevertheless, the greatest danger at present is

too swift an expansion before the personnel resources are available and before a proper evaluation of the methodology has been undertaken.

In this academic year (1996-97) a second group of schools joined the project, including schools in both the Vientiane province and the Khammoune province in central Laos. Essentially the same programme has been followed, with only small changes to the training programme. The experience in Savannakhet had suggested that it is easier to start in a group of schools, so that each school has a close neighbour (i.e. the smallest group should be two kindergartens and two primary schools, rather than one primary and one kindergarten) and this plan was followed.

There are demands for additional formal training but the implementation team and the project board feel reluctant to introduce this at this stage because of limited financial and (more importantly) personnel resources. Instead they are seeking to increase the knowledge and expertise of the expanded implementation team, which will then provide informal training at school and school group level. If, for example one of the head teachers in Savanakhet were able to lead a discussion of issues and help in the problem-solving strategies, would this not have more long-term benefit than an additional formal workshop? However, the balance between formal training and informal school development needs to be carefully thought through.

The team also aims to produce the following:

- a newsletter to be used to spread experiences and good practice between all those involved;
- a training manual, based on a combination of items from the UNESCO pack and other items which our experiences suggest are needed and straightforward enough to be used locally;
- management guidelines;
- materials for teachers and parents.

It is also clear that some thought will have to be given to the problem of child assessment and how to provide access to information and help when schools are faced with unknown situations. There will be a need for at least some staff at a national level who have a much higher level of training than is currently available. At present, some outside help can be drawn upon but this expertise will have to be available within the service at some point in time.

### CONCLUSION

The prognosis for children is better when help is available at an early age; it is also easier to give that help when they are young. Bringing in the kindergarten sector makes sense. Perhaps it is also worth considering whether integration may not be just a little easier when it is introduced at the very start of service provision, rather than when the 'mature wood' of a fully developed special school system makes 'bending' in new directions more difficult.

The experience of the Lao Integrated Education Project has shown that with careful planning and implementation, and by using all the resources available, the twin goals of improving quality for all and providing for children with special needs can go hand in hand; each initiative in the process feeds into the development, and in turn each benefits from the combined effort. Determination and co-operation are the keys to success.

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## LEBANON

# The Hadicat-as-Salam Programme for Special Education

Part of the Tadamoun wa Tanmia Association (Solidarity and Development)

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## INTRODUCTION

#### 1. About the Association

The Tadamoun Wa Tanmia Association (Solidarity and Development) was founded in 1986. The human being, regardless of race and belief, is its goal and resource. In practice, it follows the principles of the unity of a civil society and commitment to social service as a means for social change. It also believes in the development of practical, technical skills through scientific resources.

The Hadicat As Salam Centre in Hlaliye – Saida, is one example of the many activities undertaken by the Association. It is concerned primarily with the integration of children and teenagers with special needs with other members of society, and the development of a training programme for people working in special educational and social fields. This relies heavily on co-operation with, and the joint efforts of, other institutions, which also allows them to benefit from the Centre's work.

Since 1992, the Association has organised an educational programme for special needs (SN) children aged two and above. The programme arose out of a belief in the importance of early intervention for chil-

dren with special needs and the absence of special care institutions for children under the age of seven. The Association has also established a special care programme for SN teenagers (aged 14 years and above) which run professional training programmes.

The Hadicat As Salam Centre is one of the pioneer centres in Lebanon, gradually integrating SN children with other children through shared, carefully co-ordinated activities.

#### 2. The local environment

The Association is located in Saida, the third largest city in Lebanon with around 300,000 inhabitants, the majority of whom are Lebanese. There are two major Palestinian camps nearby: Ein-El-Helweh and Miye. More than 80,000 Palestinians live in the Ein-El-Helweh camp and there is a total Palestinian population of about 150,000 in the city as a whole, which is the largest Palestinian community in Lebanon. Saida has always been a city where different communities live side by side and is the most open city in Lebanon.

The socio-economic situation in Saida is similar to that in other areas of Lebanon. The economy suffers from stagnation, as well as recession, increasing unemployment and growing inflation. This has led to a diminishing of the middle classes, who in the past

acted as a security valve within the Lebanese system, and to a devaluation of the currency. In addition, there are no social security networks. The Lebanese community suffers a heavy burden in areas such as health, education, housing and food.

## 3. Educational provision

The city of Saida has 11 elementary and intermediate public (state-funded) schools which also provide for children at Kindergarten (KG) level who are aged between four and five. There are also 18 private schools which take children who are over three years of age and 19 private nurseries, four asking for nominal fees, for children under three years of age. This early stage (0-3 years) is not included within the public education system.

It is important to note the lack of accurate national statistics about the numbers of children, but it is clear that there are too few schools in the city and a great number of children to whom an education is denied.

## Children with Special Needs (SN)

The official work during the war was focused on partial financial support for a number of private social institutions which care for SN children. Since the war, over the past three years or so, the level of care for these children has increased at both private and public level, owing especially to the work of the Ministry of Social Affairs. A National Committee has been formed, comprising representatives of both the private and public sector, and of those with special needs.

The 'SN Identification Card' is one of the Committee's recent achievements. It enables its holder to receive free social and health services. The National Committee has a legal sub-committee which has produced a proposal containing 140 articles about the civil rights of people with special needs. It has been transferred to the Parliament, Chamber of Deputies for further study and discussion.

Prior to the war, five private institutions played a major role in caring and providing special education for SN children of seven years and over in Saida. Currently, about 200 SN children attend the five institutions in Saida, but this provision is insufficient to meet demand, especially for those with more severe or complex needs, so parents have had to seek an appropriate placement for their child in the capital, Beirut.

There are few statistics about SN children in Lebanon, although in 1992, the Association tried to survey a sample of inhabitants in Saida to identify the number

of children with SN under the age of five. This figure was not established, since many parents find it hard to admit that their child has special needs and started registering their children a little too late after the initiation of the programme.

Some of the difficulties facing families with an SN child are:

- the absence of institutions, private or public, which provide for severe cases; as a result, the responsibility for care and support lies totally with the parents
- the government gives partial financial support to Lebanese citizens, (via the institutions), which means that there are non-Lebanese children who are completely unaided by the institutions
- in most cases, private institutions lack the human and material resources to provide special education programmes for all the children in their care.

## PROGRAMME DESIGN AND IMPLEMENTATION

The Tadamun Wa Tanmia Association started its work in the field of special education in 1989. During the initiation period, the work focused on co-ordinating joint activities for SN and non-SN children in summer clubs and camps. Between 1989 and 1991, approximately 700 children between four and 12 years old benefited from this programme.

In 1992, the evaluation of this initiative showed that it had been a positive experience for the children, parents and educators who had taken part. The Association used what it had learned from this pioneering initiative to help develop an educational programme for teenagers with SN and for children with SN, under the age of seven. This was in addition to the existing nursery programme for non-SN children under three. This framework of programmes has allowed for the development of a number of co-ordinated activities which are discussed later in this paper.

#### 1. Programme outline

The programme for children with special needs has two major strands:

- a) The children's programme
- b) The adolescent's programme.

The total budget for the programme is funded as follows:

- 30% International non-governmental organisations
- 35% Lebanese Ministry of Social Affairs
- 20% Beneficiaries (parents)
- 15% Local Contributions.

Each of these programmes focuses on the individual needs of each student at the Centre, taking into account his or her present level of cognitive development, type of disability, chronological age, priority needs, and future environment needs. Each individualised 'formula' is then incorporated in the group programme, i.e. group activities which take into account needs common to a particular group of students and aim to enhance social and communication skills among the students within the group.

In the children's programme (Programme 1), there are two small groups of between five and six children of between three and eight years old, each having a main educator. The programme focuses on enabling them to achieve independence in daily living, through the enhancement of psycho-motor and adaptive communication skills, and the development of basic cognitive skills in the context of pre-academic training. Leisure activities make up an important part of the programme and include outdoor events, field trips and simple adapted sports.

Programme 2 serves a group of 13 adolescent students aged between 12 and 18 years. They have one educator and one teacher-assistant. The programme emphasises:

- the basic academic skills which are necessary for future vocational training
- advanced training for independent living with age-appropriate tasks
- training in social and communication skills
- pre-vocational training aimed at preparing the students for the acquisition of a vocation which would ensure proper integration in the community. Several workshops have been planned to serve this end, namely: cooking; agriculture; light carpentry; sewing and knitting, ceramics; and electrical work.

In addition to the above, there is an ongoing programme of leisure activities throughout the year which comprises mainly sports activity, educational excursions and trips.

## 2. Objectives

The Hadicat-As-Salam Centre's general objective is to offer adequate educational opportunities and a proper social environment, as well as a rehabilitative framework, to children and adolescents with special needs, in order to help them acquire the necessary skills for integration in their community.

This objective can be broken down into several subobjectives as follows:

- to design and implement appropriate educational plans to meet the needs of every child in the institution, through the professional advice and careful supervision of specialists in the field of educational psychology and special education
- to provide a stimulating environment ensuring the development of each child's social skills through the application of behaviour modification techniques and other educational strategies aimed at fostering socially-acceptable behaviour
- to offer students training facilities in pre-vocational skills by providing a choice of sheltered workshops, where each student is placed according to his or her preferences and needs as perceived by the staff in charge.

## 3. Mechanisms of early identification of children with special needs

This aspect of the programme applies only to the children referred to us who are below five years of age. The mechanism for early identification consists of the following stages.

### Stage 1

This is a preliminary interview with the child's parents or principal carer(s). It is a lengthy interview carried out by the Centre's social worker, in the presence of one or two of the administrative decision-makers. The interview focuses on the prenatal, natal, neo-natal and early childhood history of the child and tries to elicit as much information as possible from the respondent(s) concerning the medical history, as well as the present behavioural problems, of the child.

### Stage 2

This is a screening and assessment session, during which the school's psychologist administers a battery of screening tests in order to draw up a diagnostic profile and detect areas of weakness presented by the child. These will then determine the basic curriculum areas for his or her educational programme. This information is later discussed in a private meeting with the school administration in order to reach a decision on whether the child will be offered or refused a place.

In case of refusal, the child will be referred to another specialist institution.

If a child is admitted there are two more stages.

## Stage 3

This is a crucial probation and observation period. The parents are asked to bring in their child for a probation period of one to two months, during which observation of the child enables staff to determine to which group the child belongs, to identify the needs of the child and to establish the major elements of his or her educational programme.

## Stage 4

This stage comprises programme design and task analysis. Based on the observation recorded during stage 3, the school psychologist and the educators design an individualised educational programme for the child. The programme is carefully tailored to fit the priority needs of the child and is set out in great detail, ensuring that it is comprehensible to the child's parents. It is important that they understand the objectives to which the staff is working and the methods and materials used in the classroom. Involving parents in this way also helps to ensure continuity between the school and the home in the whole educative process.

## 4. Monitoring mechanisms

To ensure that the entire educational and vocational programme is running smoothly, a sound monitoring strategy has been adopted, based on regularly-held evaluation meetings between the administration officials and the educators in charge of the children. During these meetings, the objectives set for each child, as well as for the group as a whole, are discussed and revised as necessary. The methods used in the classroom are also discussed, and suggestions are exchanged in the light of each child's development. Any problems encountered (a child's condition, difficulty in implementing a certain approach, material needs for the classroom, etc.) are carefully noted and a monthly meeting is held between the educators and the psychologist where possible solutions, programme modifications, and other educational and psychological issues are discussed. The psychologist also revises all the individualised educational plans every month, focusing on the educational objectives and reviewing and evaluating the skills of each child.

## 5. Links with specialists / support services / referral services

The educational system adopted by the Centre is based on a multi-disciplinary approach and specialist services are provided for those requesting them. The services available are: physiotherapy, speech therapy, and psychiatric follow-up.

Few children registered at the Centre have severe physical disabilities, but many of them present mild forms of cerebral-palsy (spasticity, lack of motor coordination, general imbalance, etc) and these require regular training and exercise, the aim being to enable each child to obtain as much autonomy as possible in his or her movements in the environment. Similarly, many children with mental disabilities present mild to severe speech impairments which affect their ability to communicate. If neglected, these impairments are likely to affect the overall development of the child. This is why speech therapy and speech-reeducation should be an integral part of any educational programme for children with mental disability.

Unfortunately, the Centre is unable to provide these specialised services owing to the lack of available professionals in Saida who could work on a full-time, or even part-time, basis at the Centre. However, a sound referral system has been established at the Centre with stable links with a small number of professionals in Beirut who are ready to provide these services in as systematic a way as possible in private clinics or in other care institutions.

## 6. Partnerships with parents and the community

If the potential of any educational and therapeutic endeavour is to be realised, then a solid link between the home and the school must be established and continually reinforced. At Hadicat-As-Salam, parents play an important part in the educational process, and they do this in a number of ways.

- a) They are given a copy of the individualised educational plan which they can consult at any time in order to work on the same objectives as the school. In this way, they are involved in the implementation of the plan.
- b) Regular meetings with the parents allow for the discussion of ideas and suggestions concerning the educational programme, the child's needs, the child's progress and so on. Our experience in these meetings reveals that parents have a great deal of enthusiasm and motivation to become involved in their child's education. They express their ideas, opinions and criticisms openly and in such a way that the Centre learns a great deal about how it can improve its educational and rehabilitation programme.
- c) Interested parents are invited to attend training sessions alongside the educators, in order to become familiar with special techniques and



methods for working with SN children and to help them implement these at home. In addition, all parents are requested to participate in activities with the group of children in which their child is placed, and they are asked to prepare beforehand.

- d) Regular monthly visits to the families are made by our social workers, the aim of which is to ensure social follow-ups for all children. These visits are carefully structured and are discussed in staff meetings to ensure that everyone has up-to-date information.
- e) A parent committee has been formed, the functions of which are to: reinforce parental participation in the vocational workshops; facilitate the communication network between parents and the school; provide a means of representation for parents in administrative meetings.

## 7. Staff training programmes

The staff in charge of the education of children and adolescents with special needs undergoes a yearly field-training programme at Hadicat-As-Salam

consisting of conferences, lectures and workshops in the following fields:

- special education
- speech therapy
- essentials of occupational therapy
- behaviour modification techniques
- classroom management
- design of individualised educational programmes
- basic assessment and screening procedures
- early identification of disabilities
- principles of early intervention
- development evaluation.

Professionals in the fields of education, psychology and social work are involved in the delivery of this training programme.

For the first few years, the executive board of Hadicat-As-Salam designed the training programme, but as a result of continuous intensive training, we have reached a stage where members of staff can define their priorities clearly and precisely. For the past two years, technical and professional needs have been discussed by the educators, social workers and administrative supervisors and these have then formed the basis of the annual training programme.

Our staff also participate in workshops and conferences outside the Centre and some staff are attending a parallel two-year training programme offered by the Department of Special Education in the University of Saint-Joseph in Beirut, which leads to a technical degree in special education. This programme emphasises the theoretical aspect of special education and has a clinical focus (etiology of disabilities, diagnostic measures, types of disabilities, understanding of behavioural and emotional disorders, etc.).

The continuous training includes administrators and decision-makers as well as educators. They participate in conferences and sessions held at educational and administrative levels both in Lebanon and abroad. Both constitute a real opportunity for us to share our experience with others and to learn from the experience of others.

## 8. Outreach work

Since the ultimate objective at Hadicat-As-Salam is to ensure the integration of disabled people in the community, all our efforts are geared towards the realisation of this goal.

Integration is pursued at the children's level; an annual plan of activities is prepared which aims to integrate SN children with their non-SN peers in the nursery programme.

The programme includes:

- participation of the SN children with non-SN children in daily living activities and free activities (indoor and outdoor play)
- engagement of the SN children in some cognitive activities alongside the other nursery children (over two-and-a-half years), under the supervision of the special educator
- holding ceremonies and parties for both SN and other children, with the participation of their families
- inviting SN and non-SN children from other institutions to share in celebrations within the Centre
- involving a few SN children alongside non-SN children in a summer activities programme.

This plan of integration includes only the SN children who have the potential to benefit, and activities are organised to meet each child's developmental needs. To date, three children from the special education section have been placed in the mainstream kindergarten classes following educational and social rehabilitation.

Wishing to build on and develop this work, in 1994 we joined the 'Co-ordination Committee for Integrating SN Children in Normal Schools'. It is a

non-governmental committee consisting of interested individuals. Its objectives are as follows:

- Identifying SN children who are ready for being integrated, planning their individual programmes and follow-up, and training for the teachers in charge.
- Examining rules that support or hinder the integration process and creating proper legislation to further that process.

Presently, this committee is concerned with undertaking relevant research and studies, and facilitating the exchange of experiences among institutions and individuals.

## PROBLEMS AND MAJOR ISSUES

## 1. Attitudes in the community

It is true that many positive changes have occurred over the past ten years in the way in which disability is dealt with in Lebanon. There are, however, many problems still facing the disabled person and severely hindering his or her total integration into the community.

One of the positive changes mentioned above is an increase in awareness via the media (TV programmes and documentaries) and seminars and conferences conducted by professionals. In a parallel way, new special care institutions have been founded in different regions in Lebanon in an attempt to serve more deprived areas. Moreover, academic programmes in special education have become part of university curricula which encourages an increasing number of students to enrol in such programmes and get more involved in the world of disability.

However, all this does not seem to be enough, for there are still many misconceptions stigmatising disabled people in the cities as well as in the village. Disabled people are seen in general as pathetic, helpless people, and most of the time, as parasites living off society and their parents. Stereotyped judgements prevail, condemning them to be dependent forever upon others for their material survival. The vast majority of the public is ignorant about the types and degrees of disability. For example, even now, mental disability is still confused with mental illness. The despising and rejection of disabled people are at one end of the continuum, and charity and pity at the other end. There is no in-between position.

It is more and more difficult for the notion of integration to be accepted and applied in a society dominated by these two extreme views of the disabled person.

Parents of disabled children still feel marginalised, misunderstood and in many cases, wrongly judged. In some areas of Lebanon, superstitious beliefs still prevail, and the incidence of disability in a family is believed to be a result of the wrath of God over that family.

As for the schooling and employment of disabled people, the Lebanese community does not yet seem to be ready to accept the idea, despite the fact that serious attempts have been made in the last two years to promote the integration of disabled children in mainstream school settings. One of the main barriers to achieving this is the unwillingness of the community to accept the idea of their 'normal' child being educated alongside a disabled child. The employment of disabled people is similarly affected: non-disabled people find it hard to accept working alongside disabled colleagues. These are common attitudes, manifest in the rejection, humiliation and even abuse of disabled people.

Nevertheless, the overall picture is not as alarming as it was ten years ago. For example, the Lebanese Government now has a Ministry for the Affairs of the Disabled and there is a clearly felt desire to change the status of disabled people.

#### 2. Limited resources

Like all non-governmental organisations working with disabled people, our organisation has a continuous need for resources – both material and human – to enable it to improve its services.

A special budget is allocated every year for the purchase of new educational and recreational resources to help improve the quality of our teaching methods. This budget is generally insufficient, owing to increased prices in the Lebanese market. Financial contributions from the families of our registered children do not cover the total cost for a child participating in this programme, which is expensive because it includes various specialist services (psychology, psychiatry, physiotherapy, etc).

It is worth mentioning that workshops sometimes provide staff with an opportunity to produce educational resources from scratch, but unfortunately this solves only a small part of the problem.

Part of our training programme is open to educators working in other institutions, and the centre attaches great importance to the development of human resources. It is always done for the benefit of as many

workers (in the field of early childhood education) as possible. This idea is not financially-driven (participants usually pay nominal fees); including others in our continuous annual training not only develops the potential of the workers but also improves the quality of work and services being offered by their institutions.

## 3. Availability of trained personnel

Perhaps the most significant problem facing all special care organisations in Lebanon is the non-availability of trained personnel to work with disabled people. The general lack of awareness in the community regarding the status and the needs of disabled people is reflected in the kinds of people who apply for work in special care institutions. They are usually people with no previous experience and a limited educational background who want to join because there is nothing else they can do (!) and also because of the tendency to do charity work. The professionals and experts who work in these organisations are there on a part-time basis as consultants on special service agreements because the majority of such organisations cannot afford to pay salaries for full-time professionals. However, more university programmes are now available in Lebanon and university students are starting to show some interest in the field of special education. It is hoped that these graduates will join special care organisations and professionalise the services the organisations can offer.

As for the personnel currently available, it is true that they lack the professional background, but as we have previously mentioned they are undergoing an annual on-the-job training programme. Furthermore, most of them are completing their university studies, which helps ensure that they are continually developing their experiences in this field.

## 4. Identifying/reaching children with special needs

The most crucial issues facing families and special care institutions in identifying cases and the problems of children with special needs are listed below.

- a) Owing to the absence of information and guidance sessions on basic health, parents are ignorant of developmental problems which might later affect their children's competencies and abilities. In addition, existing health, educational and social frameworks contribute little to the recognition of special needs at an early stage in a child's life.
- b) There are relatively few specialist personnel in the region who are able to recognise problems

and diagnose them scientifically and objectively. As a result, parents usually go to a family doctor who studies the child's health in general without recognising the need for or attaching importance to professional and educational intervention.

- Scientific diagnosis is usually unaffordable and forms a major obstacle to early intervention in a child's health and educational needs.
- d) There is a lack of either private or public agencies which can respond to the above-mentioned problems. If such channels existed, they could:
  - raise parents' awareness of the child's problem.
  - transfer the child to the proper diagnostic framework.
  - direct the child to the appropriate special education programmes.

## **CONCLUSION**

Our experience of working with SN children has been rich at many different levels, working with parents as well as children.

### The child:

we have gradually noticed and recognised the importance of early intervention and the early detection of any problems. The pre-school programme has contributed greatly to the initiation and development of specialised educational programmes.

#### **Parents:**

we felt that most parents responded positively to our programmes and developed a new perception regarding SN children and ways of working with them. Parents have started accepting the fact that their children have special needs, and are beginning to devote more time and effort to caring for them in order to create the opportunity for better development.

#### Integration:

integration programmes have opened new horizons for some SN children to interact with the local community in a number of different ways. In Saida, there has been a positive change in the attitudes of non-SN children and their parents; their increased understanding and acceptance of SN children has contributed to the success of the programme.

### **Training:**

it is important to recognise the role of the continuous professional training of workers. A training which unifies concepts and methodology in field work, fosters a team-work approach among the workers and helps overcome the need for professionals. However, the need for trained professionals continues to be crucial in such programmes.

#### Sharing:

it is important to exchange ideas and experience at local, regional and international levels. Our experience was enriched by opportunities to participate in conferences, study groups and visits within Lebanon and abroad and opened new horizons for us. Hence our reinforcement of the idea of exchanging research and experience at different levels and in different areas relating to early childhood education.

Our experience is modest and is just starting. However, it has contributed to the establishment of new concepts and practices. Our base is the belief in equality of rights for **all** children and equality of opportunity. Our work has been only the beginning of a long endeavour, to gain the necessary experience to enforce the basic rights of SN children and to develop appropriate services which respond to their needs.

## **APPENDIX**

## Number of participants

Types of disability: developmental delay – mild mental disability – Downs Syndrome – cerebral palsy – speech and hearing impairments – communication disorders.

| Year  | Number of children | Ages                  | Number of groups |
|-------|--------------------|-----------------------|------------------|
| 92-93 | 6                  | 2- 4                  | 1                |
| 93-94 | 20                 | 2- 4<br>5- 7<br>13-18 | 3                |
| 94-95 | 27                 | 3- 5<br>6- 8<br>11-18 | 3                |
| 95-96 | 25                 | 3- 8<br>12-18         | 2                |
| 96-97 | 30                 | 3- 6<br>7- 9<br>12-19 | 4                |

N.B. Annually, around 25 children undergo the screening tests administered by the Centre's psychologist on a consultation basis. Usually, if they are not within the Special Education Programme's criteria, they are referred to other specialist institutions.

## **MAURITIUS**

## Early Stimulation and Intervention in Special Needs Education: the APEIM Experience

By APEIM

## INTRODUCTION

APEIM is the Association de Parents d'Enfants Inadaptés de l'Ile Maurice. It is a non-governmental organisation (NGO) which has been working for 26 years on behalf of people with mental disabilities.

When APEIM was founded, there were no services for these people and their families in Mauritius. Since then, 3,025 families have approached APEIM for information, support, help and services; regular services are currently provided to about 400 families. Children are referred to APEIM by doctors, hospitals, pre-school establishments, schools and even by neighbours and friends.

### APEIM's activities include:

- regular services:
  - specialist schools,
  - integrated classes,
  - vocational training unit,
  - early intervention programme,
  - home visits,
  - consultancy,
  - counselling and therapy;
- parent empowerment;
- information and training;
- fundraising.

## **Demographic information**

The population of Mauritius is 1,094,430. Of these, 13.4% live in the capital, 31.6% live in urban areas and 55% in rural areas. The infant mortality rate is 1.96%

Sixty seven per cent of the population is Indian (Hindus and Muslims), 31% are of mixed origin (mainly African and French), and 2% are Chinese. A range of languages is spoken at home; the majority speaks Creole (61.7%) or Bhojpuri (19.1%).

There is a falling birth rate and a stable death rate. There is 'full' employment, although two per cent are out of work and this figure is increasing, and there are 9000 temporary foreign workers.

The average number of children per family is three. There are often two or three generations of one family living under the same roof.

The rate of economic growth stood at 5.5% in 1995. The main economic sectors are: manufactured goods for export only (e.g. garments, jewellery, watches), sugar and tourism. The main asset in Mauritius is our human resources, but the country needs:

- · more able and trainable workers
- improved primary school teacher training (only 35% hold a diploma or certificate)
- improved secondary school enrolment (15%)
- improved pass rate for primary school examination, the CPE (48% repeated last year).

## SOCIAL AND EDUCATIONAL ISSUES

#### **Education**

There is a highly competitive primary education system, leading to a final ranking examination (CPE) which includes assessment in four academic subjects: French, English, mathematics and environmental studies, and in an oriental language, which is optional.

There is a multi-language policy for children over five. Children are taught to read and write simultaneously in English, French and an oriental language which is chosen by the parents.

Class sizes are large, with a pupil-teacher ratio of 1:45.

Pre-school and child care

There are 1100 kindergartens, of which 960 are private and 140 public.

Child care is organised in two phases: birth to three years and three to five years. There is no regulation of nurseries and crèches. Private kindergartens can be found all over the island but the type and level of service varies enormously.

A grant of Rs 200 (US\$ 10) per month is provided for four and five year-old pupils attending kindergartens registered by the Ministry of Education. These registered kindergartens are visited and advised by inspectors, and basic standards for kindergartens have now been introduced. There is a lack of trained staff, which inhibits development. There are no figures on children with special needs; neither is there a policy. Indeed, there are no figures relating to disability in Mauritius at all.

## Children with disabilities and their families

The attitude of the community to disability is positive, but not inclusive. There is still much ignorance, fear, misunderstanding and exclusion of disabled people. Families with disabled children, particularly those having severe behavioural difficulties, autism or cerebral palsy, often experience isolation. There is a lack of public information about disability, and raising public awareness and understanding of people with disabilities is an important issue.

An increasing number of mothers work and this can lead to new problems, such as stress, neglect and a

lack of time for stimulating their disabled children. However, there is a relatively large number of extended families where a grandmother is involved in the care of children with disabilities.

A high percentage of disabled children are left at home without access to education, and the system relies on families taking the initiative to seek advice and services. Information for families needs to be better and more easily available.

The Ministry of Social Security gives a low level of financial assistance to families. It provides Rs 620 (US\$ 30) a month for severely disabled children if the mother has to stay at home and if her yearly income is below Rs 42,000 (US\$ 2100). (NB:check meaning, unclear). Once a disabled child has reached 15, the government provides Rs 1,055 (US\$ 53) a month. The costs of transport are refunded for children attending special schools.

All specialist services rely on NGOs: there are nine catering for children up to the age of 10 and APEIM is the only one catering for children under 5 years of age. There is no systematic screening and early detection programme functioning at the national level.

The Ministry of Education does not have a policy for inclusion and there is a lack of space in special schools. However, it is possible to integrate children under six years of age in kindergartens, except for those with severe cerebral palsy, severe hyperactivity and behavioural difficulties. Integration is more common in the rural areas than in urban areas.

There is a lack of all types of professionals, including teachers and doctors trained in the field of disability. Training is therefore a key issue for development.

## PROGRAMME DESIGN AND IMPLEMENTATION

The Early Intervention Programme, launched in 1983, is part of APEIM's service provision, and caters for children from birth to six who have a mental or multiple disability. To participate in the programme, children must be registered with APEIM.

The Early Intervention Programme is a mobile service, catering for parents and their children in their own localities. The objectives of the project are to:

- listen to and support parents
- provide them with guidance on stimulation and education for their children

- teach them how to use technical tools
- provide information through video, discussions, practical workshops
- lead sibling and handicraft workshops
- provide opportunities for extra-curricular family activities – e.g. outings
- develop means of inclusion in society and kindergartens.

This service caters for infants and children from birth to six years. Its purpose is to train families in low-cost and simple intervention techniques to enable them to help in their child's development, whether their child has a mental disability or multiple disabilities such as Downs syndrome, autism, birth anoxia, epilepsy, rubella syndrome and cerebral palsy. Information on their child's progress is provided regularly to parents so that they can better stimulate their child, minimise disability and develop positive parenting techniques.

Parents and children meet on a weekly or fortnightly basis in APEIM centres or in parishes or social welfare centres in St Paul, Port Louis, Pamplemousses, St Julien and Plaine Magnien.

Appropriate goals and teaching sequences are set for each child, and there are regular tests which assess progress. Parents accompany their child, which enables them to learn from and exchange experiences with other parents. At the beginning of a session, parents watch the teacher working with their child. When they have grasped the content of the activity, they help in the group with their child and/or with other children. They are taught how to continue and develop the activities, mainly in the home environment. Talks, parents' meetings and workshops for families and siblings are organised at the end of each term, to allow them to share and to learn from each other.

This programme has proved to be very beneficial for the participating families. The progress of many children has been followed; some have been integrated into mainstream kindergartens and primary schools and some have been placed with other APEIM services.

The Early Intervention Programme was launched with the financial assistance of NFPU, a Norwegian association which financed the programme for 10 years. CBM (Christoffel Blindenmission) has been funding half of the project costs for the past three years. United Way, a Mauritian association, helped to finance the other half of the project for two years. A French association, Kilometres de Soleil, has made a donation which will enable us to run the early intervention programme this year.

## WORKING TOWARDS INTEGRATION

There is no specific mechanism for early identification in Mauritius, but APEIM's work is now quite well known to hospitals, private doctors and the public. Children come to APEIM via many different routes – doctors in hospitals, neighbours, friends, teachers and so on.

Between 1970 and 1980 kindergartens were isolated and people were unaware of the importance of sending their children to kindergarten. In 1980, a burgeoning of the number of kindergartens coincided with the expansion of the EPZ and more women going out to work. The majority of kindergartens were not regulated and did not share a common structure or educational purpose. Anybody could set up and run a kindergarten. Many have done so as a business enterprise and, in these cases, the interests of the children are often not a priority. Many kindergartens accepted children with disabilities, often because of personal contacts with the family, for financial gain or other professional reasons.

In those days integration was still a dream to be realised. After five to six years had passed, some parents in rural areas started sending their mentally-disabled children to their local pre-school (i.e. school before primary school). By accepting children with a mental disability, these schools in rural areas took a first step towards integration. Children living in villages were more 'accepted', because at that time the teachers were running their own schools. There were few schools and everybody knew their neighbours. APEIM started visiting the schools where children with mental disability were integrated, creating a positive relationship with these mainstream kindergartens.

The next stage in the development was that the government required all private schools to register, and inspectors started to visit the schools. Training for teachers from private schools was introduced, and they included information about special schools. Teachers were taught that children with disabilities should be placed in special schools and it therefore became quite difficult to achieve any level of integration.

The frequent visits of inspectors to the schools reinforce this negative attitude, because they too are convinced that special schools are the solution. To help put the case for integration, the APEIM team started to visit pre-primary schools to explain the principles of integration. As a result of APEIM's regular contact with inspectors, they have been persuaded of the

benefits of integration. APEIM has also worked with the teachers, introducing the ABACUS assessment to enable them to detect children with a disability and refer them earlier to APEIM, while keeping them in school.

If a disabled child has been in a nursery, and if there is a kindergarten attached – and nearly all kindergartens do have attached nurseries – then transfer of that child from nursery to kindergarten at the appropriate age is usually automatic.

APEIM's objectives concerning integration are very clearly explained to the pre-primary teachers. The main objective is to guarantee disabled children the right to grow up, learn and live as able-bodied people do. Our past experience has shown that the children who have benefited from integration develop better and achieve more than those who stay at home. Parents feel more a part of the community and have fewer negative feelings. Life is easier for them and for all their children.

All families look after their children at home (there are no homes for disabled children in Mauritius). The majority of Mauritian parents overprotect their child if he or she has a disability. This close relationship means that separation from the child is difficult. Once the first step in separation has been achieved, the child can look forward to learning from and with others outside the family.

In most of the cases concerning integration, only children with a mental disability are accepted. It is more difficult for those with multiple disabilities, hyperactivity or autism. Sometimes such children are accepted if the mother stays with her child at the school, especially during the first weeks. If the mother is at work, then she has to pay someone to accompany the child. Most children with Down's syndrome are in nurseries and kindergartens.

Over the years, APEIM's intervention has become helpful when the parents are having difficulty in finding a kindergarten. As far as possible we let the parents do the maximum and we intervene only when it is needed.

## **Training**

Some schools ask us for help and request a special programme which can be used in specific areas of a child's developmental programme. Site visits to pre-primary schools often involve an explanation of APEIM's special techniques and the sharing of information about our work.

APEIM team members meet with pre-primary school teachers, at their request, in schools where disabled children from our stimulation groups are integrated. These meetings generally take the form of an open discussion where teachers share the problems they encounter when teaching children with disabilities.

Every October APEIM runs courses for pre-primary school trainee teachers in collaboration with teacher training organisations. The courses provide a basic knowledge of special education and integration and develop an awareness of the type of mental disability which the trainees may encounter in their schools.

## **Barriers to integration**

The major problems we encounter when dealing with integration are the attitudes of the public and the lack of staff training. There is still much work to do in changing people's attitudes. Teachers are initially resistant to and apprehensive about integration but once they have received information and training, their attitudes change quite rapidly and they are willing to try integration.

There is also much to be done to change the attitudes of other parents in the kindergartens. When they are not 'prepared', they can easily ruin an integration programme, so awareness-raising for the parents is therefore very important. We have to reassure them that their own children will not begin to behave strangely and that a disability is not contagious. When necessary, meetings are held to explain some of these points and to try to pre-empt negative reactions.

In spite of all the difficulties, APEIM is still hopeful that integration will succeed, although in primary schools integration has so far proved problematic. As there is no policy on integration, it is difficult to make progress and our attempts have seldom been successful. First, the parents have to deal directly with the person in charge of the school, who then contacts

the inspector. The latter will inform the Ministry of Education about the case, and the Ministry then makes a final decision concerning the integration of the child. Often, parents find this a slow and cumbersome process, so they become discouraged and give up. As a result, many children who need to be in primary school, especially those with a physical problem or mild learning difficulties, stay at home. When a child has been identified as having a disability, whether he or she is allowed to stay at school depends on two major points:

- the personal view of the headteacher
- the inspector's view of integration.

APEIM actually prefers to encourage the integration of specialist classes in primary school. This seems to be the best solution, given the number of barriers to integration, which include the policy language, the teacher/pupil ratio and the highly competitive system. Some of our pupils are integrated for non-academic classes when possible – e.g. religion, art. Full inclusion could only be realised if important reforms were implemented.

Since January 1997, the government has given a grant to all children aged four to five who are attending kindergartens. This has led to a new problem which is threatening inclusion. Often, disabled children stay at kindergarten between the ages of three and eight. Because they do not fit the age criterion for a grant, some kindergartens which were formerly open to integration now refuse to accept disabled children. This is a new struggle for APEIM, which has begun by meeting with the Minister of Education to discuss this important issue and to make him aware of the value of inclusion in kindergartens and primary schools.

### CONCLUSION

Many lessons have been learned during the years since 1983, including:

- NGOs must always be accountable and reliable.
  Their image is very important when trying to
  reach and persuade the community, the public
  and policy makers;
- adapt the programme to economic change and the needs of the family;
- do not be aggressive or too demanding
   take it one step at a time;
- first make contact with the people you already know:
- multiply intervention in local structures: go to schools and meet the headteachers and teachers as often as needed;
- use personal relationships/contacts, but stay professional;
- give free professional support to kindergartens and schools in order to reinforce good collaboration;
- accept requests from the public, such as pre-primary teacher training, even if that is not your job – try to do something;
- involve the parents, especially mothers, in the kindergartens when you integrate children with severe disabilities or behavioural difficulties;
- reinforce the supportive links between parents who can give others the courage to fight for inclusion;
- adapt knowledge received from foreign countries to the needs and culture of your own country;
- accept that inclusion is long term work. Changes in attitudes are slow and we must remain steady and persistent in our actions if the aim is to be achieved.

**PORTUGAL** 

## Águeda's Experience: a social movement that made its history in integrating socially disadvantaged children and groups into the community

By ROSINHA MADEIRA

## INTRODUCTION

In this paper we intend to share our experience as educators and social actors who, for 20 years, have been working for the integration of children and social groups who are discriminated against.

Following the Revolution in April 1975, a movement began which stood for the unconditional integration of children who were denied social and educational acceptance in the community. This integration was seen as a legal expression of the recognition of equal rights for every person in the community.

The whole process of intervention has been undertaken by an open group of professionals and non-professionals endeavouring to work toward this principle and driven by the search for social change which is shared between parents, professionals and the children themselves. This group set up the Bela Vista, an integrated educational centre, which is, even today, a space which makes possible the development of new responses to the needs of children,

families and communities who have limited access to social opportunity.

The Bela Vista started as a nursery school in which 20% of vacancies were reserved for children with special needs and was, from early on, a space in which the integration process was shared as much by children with and without special needs as by parents and educators. Integration was viewed as a challenge, presenting the need to develop new attitudes and knowledge.

This was also the start of new services for children and the setting up of close relations between parents, other professionals and regional institutions, resulting in the creation of many other structures which support children and local projects in the areas of health, education and informal community networks.

Águeda's experience, which is reflected in many other institutions and local projects, needs to be told as a process of communitarian intervention, in which the integration of children who have special needs and/or are at a 'high risk' in social terms, was a key factor in social change and the community's development.

## BACKGROUND AND THE MOVEMENT'S BEGINNINGS

## 1. The Region of Águeda

Águeda is a Region with nearly 45,000 inhabitants, situated in the District of Aveiro, located on the central coastline of Portugal. It is part of a geographical area that has suffered many changes since 1950 because of the speed at which industrialisation has taken place.

The rural way of life was abandoned, but there was no reorganisation of social structures to replace the traditional, rural ways of solidarity. Over a short period of time, many farmers left to work in industry. Since the 1970's, many of these new workers have become businessmen, contracting other families who came looking for work.

This process led to an obvious material improvement for a large number of families born in the area, but there was a lack of housing and social integration for the migrant population. Migrant families experienced problems in finding employment and housing, and suffered financial hardship, finding it difficult to access social aid. This created increasing vulnerability and social dependence for these groups.

Thus there was a subordination of communitarian life to industrial production. In such a community, children and old people are 'at risk' and in need of support, which is now provided in an impersonal, institutional way without a feeling of 'solidarity' and respect for personal differences, both of which are necessary for good family life. The children and old people who had particular needs were discriminated against because their 'differences' disturbed the normal routine of this new way of life.

As we experienced and understood the possibilities for and obstacles to the social participation of children with special needs or those who were otherwise disadvantaged, we began to see the integration of all people and groups as a human problem, a collective problem for society and not just a technical problem.

The integration of children and young people with special needs was also seen as a means of accomplishing a more global social project, whose resolution should involve not only the children, families and specialists, but also the whole community of Águeda.

## 2. The beginning and dynamics of the communitarian intervention

In 1975, an association for parents of 'deficient' children (children with special needs) from the city of Oporto¹, came to Águeda to denounce the lack of any educational structures and social aid for children and young people with special needs and their families. We recognised that the right to public and free education embodied in the Constitution was being denied to these children.

A small group of parents, professionals and non-professionals from Águeda visited several places in the region to identify these children, young people and adults who were unknown to anyone except for their close family and neighbours. We found examples of great loneliness, not only for children but also for their families. Many of them were born and grew up in their homes; they lived together and were cared for exclusively by their family. In a very few cases, the children and their parents received some help through consultations at rehabilitation centres, located in distant towns.

The recognition of the difficulties experienced by children with special needs and their families in their daily life created the right conditions for professionals from several sectors, parents of different social groups and other agents from the community to organise themselves to develop local responses to the isolation of these children and families.

The creation of the Bela Vista nursery school was an initial response which gradually sensitised other people and groups to the need to end the passive marginalisation of these children.

The press, the meetings between parents of children with or without special needs, the new institution and above all, the continuous investment in finding ways of responding to new challenges, provided a catalyst for change, resulting in new efforts by the community to accept and respond to these children.

One of the unplanned effects of this action was the creation of a special school. However, the school was not against the idea of integration and did not replace the work at Bela Vista and other nursery schools in the Region.

Two years later it was some of these teachers in the official school who accepted the challenge of integrating children with serious difficulties in their classroom. They were stimulated by the evidence of nursery

<sup>&</sup>lt;sup>1</sup> This city is about 80 km from Águeda

school educators and parents who had learned the human value and the social meaning of living together, as well as the value of shared learning between children with different characteristics, capacities and needs.

The care of those who are more dependent, the solidarity based on respect for 'difference' and for the freedom of each individual, have now been brought back into people's consciousness, not in the form of the traditional values of a rural society in which children, adults and old people lived their daily life together, but as an understanding of the need for a collective life in which everyone needs to learn how to live together.

The participation of children in introducing and promoting the idea of integration was as important as that of adults. They too worked at improving sociability, communication and the quality of the human relations in small groups, face to face.

## 3. The development of a new policy

In 1975, Águeda had only one crèche that belonged to a wool factory and four nursery schools: one belonging to the state; two belonging to the church; and one privately owned. Two of the institutions were residential – schools for orphan children or children from very poor backgrounds. There were 42 public (state) primary schools, one preparatory school, two teleschools and one secondary school.

In these educational spaces, only two children were integrated, one with spina bifida and one who was partially deaf, although through contact with 'basic groups' and schools we confirmed that there were other children with learning and behavioural difficulties whose problems had arisen owing to their family situation. According to the teachers, this did not justify the need for any additional educational support.

## INTEGRATION IN ACTION

#### 1. Infrastructure

In this same period in Portugal, the education of children with moderate and severe learning difficulties was offered only by large institutions of special education, or by private schools located either in big town centres or in central areas of the inner part of the country. For children with mild learning difficulties there were some special classes in Lisbon. Children with behavioural problems were also hospitalised by Child Mental Health Centres in psychiatric hospitals in Oporto, Coimbra and Lisbon. For children with physical and sensory deficiencies there was only one centre of physical rehabilitation and one reception centre for children with cerebral palsy, located almost 300 km from Águeda. There were also big institutions for deaf and blind children.

All these institutions were financed by the Ministry of Social Welfare. The social educational integration in mainstream education was reserved only for children with physical and sensory problems. In these cases the children received support from Ministry of Education peripatetic teachers who had responsibility for one or more districts of the country. Only 10% of children with special educational needs were covered.

With the increased experience of integrating children with learning difficulties in nursery and state schools in Águeda, came other positive responses to integration from parents' associations. Between 1979 and 1981 these contributed to a decrease in the number of new special schools. In this phase, Águeda's movement was a point of reference for the political decision that led to an expansion of the work of peripatetic special education teams in supporting the integration of children with a wide range of special needs in mainstream schools. An alternative had been created which guaranteed the rights of children with learning difficulties to education, one which avoided their isolation from other children and adults in their community.

## 2. Formal support and resources for integration

In 1981, Águeda's Special Education Team was one of the first regional teams to be created to support the integration of all children regardless of the type and degree of their disability. This team gave status to the work of those at Bela Vista and to those who supported the integration of children with physical, sensory and learning difficulties in mainstream education.

There were already 153 children with learning difficulties integrated in public schools. The children with severe learning difficulties could also attend extra curricular activities at a centre which was run from Bela Vista and created as a complement to school.

The teachers in this team, just like those from Bela Vista and other nursery schools which were integrating children with special needs, did not have any specialist experience of special needs. An informally-constituted peripatetic group, comprising one educator, one social assistant and one doctor, was established to work with parents and educators from mainstream education. and with the special education team, in the analysis of the process of integration for children in their family, nursery school, school and other social contexts. The common interest of these different teams and groups was to find and invent opportunities for social participation in each of these contexts. Such opportunities have to be compatible with a child's resources, bearing in mind their emotional, intellectual and social needs, as well as the expectations, conditions and needs of their family and community.

Individual educational programmes sought answers to a range of questions:

- What are the problems that worry parents and educators?
- What does the child need to learn to increase his or her autonomy, self-esteem and participation in family life, school and peer groups?
- What resources are available?
- What resources is it possible to create?
- What can each person teach (where, how and when)?
- Which resources is it necessary to create in the medium term?

These programmes were registered in a book where new ideas and innovative approaches were also recorded.

Whenever possible, the child would be asked about his or her likes, interests and worries. Educators often asked the child's school friends or brothers and sisters, to discover his or her likes and dislikes and what he or she could do in and for the school group.

The special education team is now made up of 28 educators, specialising in different areas. They support the integration of children and more dependent young people up to the end of primary education, thereby facilitating access for these young people to preparatory education (fifth and sixth school years), secondary education and higher education.

Some young people with severe learning difficulties attend a Centre for Special Professional Training, between the ages of 14 and 16. At the centre, staff and professionals from the special education team, co-operate in the development of a curriculum based on the principle of education in school and in other social-educational settings in its community.

## EARLY INTERVENTION IN THE COMMUNITY

## 1. The early work

The same group that co-operated in the development of educational programmes for schools and nursery schools, also worked with children under three years of age who were a source of concern to the community and education and health professionals. This direct contact with the community was the first example of the early detection of young children who had possible problems.

As a result of this work, the educators and trainees from the nursery education course at Bela Vista decided to visit and provide regular support to mothers of 19 children who were potentially 'at risk' or who already had development problems.

These visits involved listening and helping mothers to solve health and other problems related to their children, and finding or building toys and games with recyclable and domestically available materials. They sometimes involved other mothers and other children from the family, as well as neighbours. From this starting point, we aimed to expand the networks of social support to mothers and to increase protection for children against being abandoned or neglected owing to a lack of affection and their surroundings.

In 1982, the same educators from Bela Vista also began to develop educational support for very young children with development problems, expanding the intake in the reception year to more than 30 children.

### 2. Diagnostic and health care services

At the same time, the basic group invested in the creation of nursing consultation, which was established in the hospital of the local parish at the request of the paediatric hospital serving the entire central region of the country. Many mothers came to these consulta-

tions where problem situations and risks to the child's development were identified. This provided a strong argument to the hospital administration and mobilised public opinion to demand the creation of a public health service that could guarantee primary health care for both children and the wider community.

In 1981, Águeda's Health Centre was created. Its priorities were birth control and mother and child health. The Health Centre has been an institutional partner in most communitarian action to help solve child development and education problems. The Centre has co-operated with the special education team, nursery schools and district/regional medical services.

## 3. Multi-professional and cross-disciplinary support teams

The co-operation between the areas of health, education and social support, which was informally facilitated by the most dedicated professionals in the initial phase of the movement, was now being recognised officially as being of importance in developing services.

The development consultation and the multi-professional teams, located in the head office of the Region, were created to have a complementary role in relation to existing services in several of the boroughs. They provided advice and support to parents and health and education professionals in each borough.

The development consultation team involved a paediatric doctor, an educator from the special education team and a psychologist from the Health Centre. The multi-professional team was officially created in 1984 and gave continuity to the informal group's action, which had supported school integration in its initial phase.

Both teams have a holistic and 'listening' approach to solving the problems of the parents and professionals with whom they work. They place a great deal of importance on the enrichment and enlargement of the social networks which can provide both formal and informal support to a child's family. The teams liaise directly with specialists working in the regional services. This ensures access to information and other kinds of resources and guarantees co-operation over a child and its family's problems and needs.

These teams give priority to children and others who are socially disadvantaged and they invest in projects which aim to make easier the local, borough-level integration of services provided by health and special education teams and the social centres for child support.

## 4. Critical points of the intervention

While professionals were making integration, education and social support easier for children and families in their home, schools and activity centres, there was also an equal investment in creating new resources in the community.

Logic implies that the establishing of the necessary structures and resources to support the integration of children with special needs would solve negative discrimination against, and the exclusion of, 'different' children. But this did not happen.

In 1985, 26 deaf children, nine children with severe physical disabilities and 120 children with moderate and severe learning difficulties, were attending the public (state) schools in Águeda. In the neighbouring regions, 36 other children with special needs were also attending school in their community, with the support of their parents, teachers and peripatetic teachers. All these children, their peers, parents and teachers were growing and learning to live together, and so helping to create a new philosophy and new educational and social skills.

The teachers and parents shared their experiences through the press, seminars and meetings with other professionals, organised by Bela Vista. These exchanges were a key factor in maintaining the commitment to search for solutions to new problems arising at school. They were also an influential factor in political decision-making, generating support from the Education Ministry which led to the creation of peripatetic teams and the placement of classroom support teachers to facilitate the integration of children with learning difficulties.

However, there was still a big group of children whose lives and development were strongly limited by their parents' social status. The nature of their parents' employment was used to assess their social status.

These children were not successful at school and in their social position; they were negatively discriminated against by teachers and neighbours for not meeting expectations in cognitive and social skills. The relationship that teachers and parents began to have with the services for children with special needs made it seem as if the children's difficulties in adapting to the social rules in school and the demands of the formal curriculum were the result of an intellectual inability and emotional disturbance.

It was confirmed, however, that outside school, these same children were able to undertake tasks and responsibilities as complex as looking after younger brothers and sisters, domestic jobs, work in the fields and sometimes work with community-based groups.

On learning that intervention from the special education team could be seen as confirming the community's negative expectations of a child and his or her family, the team has been reluctant to answer schools' requests for educational support. The team has, however, created an alternative response to these educational needs which should not only be appropriate to the social context in which it operates, but also values the family's knowledge and reinforces the need for them to assume some responsibility.

## 5. Support for children at risk: community-based groups

In 1982, educators began to work with these children outside school, within their daily social and familial context. An evaluation of their relationships and the roles they adopted outside school highlighted their interest in social interaction and the importance of the informal networks of social support which help children to solve their own problems. The work of special education peripatetic teachers began to focus these experiences and resources, leading to a rapid creation of a considerable number of community-based groups.

In 1988, these groups brought together more than 500 children in the regions. All the groups had found a meeting and working space (in abandoned houses, small rooms inside churches, private underground rooms, places used to keep decorations for religious feasts, etc.), and every group had its own name and a membership of more than 20 children.

Most of the children's parents, regardless of social background, were involved in their group's activities and involved themselves in the improvement of the environment (repair work, recycling school material, needlework, etc.).

Each group has already established some means of raising money to enable it to realise a range of projects. Fundraising activities include: selling sweets, painting pots, and other handiwork made from naturally-occurring local materials or waste from industry/local commerce. Recovering public spaces and cultivating small kitchen gardens was simultaneously a significant educational activity for the children and a means of improving the quality of their experiences.

In 1990, Bela Vista set up a project team in co-operation with the Health Centre, the special education team and the local authorities. The project team's role was

to work closely with the community-based groups. It was financed by two foundations.

In 1994, the work done with children, families and social agents in each community prompted social centres to open access for the groups and facilitated the creation of nine new local associations which began to develop child support services. By 1995, the rate of coverage of child-care services was much higher than in most regions of the country. In 1995, the community-based groups were re-formed and became a social-educational project. At the same time, the target population for the services also changed.

The risk of negative discrimination which leads to the need for additional care services is particularly great for young people who stay on at school and who, in a few exceptional cases, are secretly integrated into the labour world, to help their families. There are also young mothers from 'at risk' social groups, who seek help from unofficial sources because they do not have access to and/or cannot maintain a lasting link with the social centres. There are children of incapable or inadequate parents who have health problems, or who are in trouble with the law. Children of migrant families and ethnic minorities (gypsies and Africans) are also in this group; they find it difficult to fulfil the basic conditions of life - housing, social aid and a secure job - and are prevented from settling or returning to their original home.

### 6. Training for and in intervention

A problem we have yet to solve is repeating/implementing the process we underwent in Águeda in other parishes. We have had experience of inducting professionals in our work through courses or when other groups of professionals (and non-professionals) came to Águeda to find out how to implement similar initiatives in their communities. We know that it is possible to share knowledge that when applied locally, results in the development of new responses.

Therefore, between 1978 and 1985, Bela Vista promoted annual seminars at which there was an exchange of experiences, through direct communication, photographic exhibitions and detailed documentation. The seminars were facilitated by people who shared a common knowledge and experience which helped those attending to deepen their knowledge and understanding of the process. We also explored the limits and opportunities of some of the solutions found for specific problems and of continuing with intervention.

This has been the model of training and self-learning that we have adopted, and work in small groups has included the use of instruments to record significant events and to enable an analysis of the context within which the processes have occurred and of those activities undertaken.

These instruments embody the values and principles of intervention which inform the work of Águeda's group in intervention in the community. They facilitate the gathering of factual and objective information and also provide a sense of the reality in which our intervention staff operate.

The perceptions, views and experiences of the intervention agents are seen as a valuable training resource. They enable us to begin analysing relevant problems identified by the agents, allowing objective and impartial discussion of the issues by people who bring differing perspectives and knowledge.

The community-based groups and the approach, training and evaluation of the intervention process by Águeda's movement, ensures that it does not exhaust its creative potential. It is constantly addressing and thinking about the problem of social exclusion for children and disadvantaged social groups in our community. They prevent the community from becoming complacent about the successes and make the experience the people who have achieved something, despite the odds, the foundation, motivation and argument for the development of new knowledge and approaches.

## SUMMARY AND CONCLUSION

In this paper we have outlined the story of the social movement which brought about the integration of children with special needs in nursery schools, mainstream schools and other social-educational structures in the Águeda region. This has had an impact on parents and on the authorities' political decisions about education at a national level.

It is important that Águeda's community, now rich in child support services, does not ignore the social problems inherent in its industrialised environment. This is an environment which provides an uncertain supply of migrant groups and other minorities who find neither lodging, welcoming attitudes or any other facilities to assist their integration in the community. These groups are increasingly at risk of exclusion.

We have also tried in this paper to show the interdependency of many actions and the link between the social and human context in which they were created and their institutionalisation or embodiment in other social structures.

Today, a child who is born with special needs or into a 'problem' family and/or an adverse social environment in Águeda, does not have to go through a process which, not many years ago, led to negative discrimination, progressive social isolation and the impoverishment of his or her life and family situation. Now the child is recognised as (an integrated) part of the community. The child's parents and educators from the nursery and community schools are no longer alone in working for the development of social and educational solutions which protect and stimulate the child's, and our, development.

As a group, we dream that one day we will fully implement this project. As we struggle for its accomplishment we find ourselves writing the social reality which continues to sustain the search that leads us to other worlds that exclude, or better, overlook and leave in silence other actors and people of our common history!

By 'telling our story' we want to encourage other communities to invest in their struggles against the social unfairness which affects the lives of children and groups whose 'differences' are not accepted. These are the 'hostages' of an economic progress which follows an autonomous path but has contradictions which we have to face, for the sake of a democratic project and the well-being of all.

## **SOUTH AFRICA**

## Education for All: a Programme for the Inclusion of Children with Disabilities and other Special Educational Needs into Early Childhood Development Programmes

By JUDY McKENZIE

## BACKGROUND INFORMATION

The Community and Child Development Centre (CCDC) is located in the Central Region of the Province of the Eastern Cape in the Republic of South Africa. The province is currently coping with the difficult task of reconstruction following the effects of the apartheid era. It is one of the poorest provinces in the country, with high levels of illiteracy and inadequate health services. The total population of the Eastern Cape is approximately 8.5 million, with a population density of 39 per square kilometre. Three quarters of children under 15, who form 44% of the total population, live in rural areas (Health Systems Trust and the Department of Health, 1996).

The province is divided into five or six regions; different government ministries divide the province in different ways. The Central Region focuses on the city of East London, where 43% of the population is urbanised. This figure is considerably higher than for most of the other regions.

The major areas of development for the Eastern Cape mirror national concerns. Within the health sector, there is a serious attempt to bring about universal access to primary health care through transforming systems of health delivery. Within education, the arduous task of uniting fragmented systems is largely complete and the process for implementing the new curriculum is advanced, with the phasing in starting in 1998.

According to the Interim policy on Early Childhood Development (1996) the situation which South Africa has inherited with respect to Early Childhood Development (ECD), is the result of massive neglect of the needs of young children. Between nine and eleven per cent of all South African children under six years old have had access to ECD and this has been skewed in favour of urban white children, with rural black children being the most disadvantaged. The problem is not only with the level of provision but also with quality: 'Not only are very few infants and children catered for, but even fewer receive an appropriate ECD experience and therefore have an abrupt introduction to formal learning.'(Interim Policy, 1996)

Children with disabilities are even more disadvantaged within the existing system. For families in rural areas, access to early identification and intervention services is limited. However, some areas benefit from community-based rehabilitation services (Schneider, 1996) and in some provinces, the welfare department provides grants for families with children with disabilities. For many rural families, the social worker is the only source of help.

Once children with special educational needs (SEN) enter educational settings, they receive very little support from the psychological or remedial services. Health and welfare services have the most visible profile in dealing with children with disabilities, and teachers often therefore have the perception that disability is the responsibility of those services rather than of education (McKenzie and Mcleod, 1995). Consequently, very few children with SEN are involved in ECD programmes. In a survey of learners

at CCDC (McKenzie, 1996), it was found that about one per cent of children in ECD programmes had obvious disabilities, whereas the prevalence of disability in the country as a whole is estimated as being in the region of 5.21%. (Schneider, 1996).

## 1. Policy and legislation regarding early childhood care and education

Government policy for ECD provision targets children presently outside the school system who are between five and nine, and children who are at risk below five years. Children over five will be provided for within the formal education sector in the Foundation Phase of General Education and Training, once the implementation of the Reception Year has occurred. For children under five, an integrated policy involving Education, Health, Welfare, Housing and other government departments, in collaboration with communities and non-governmental organisations (NGOs) will need to be developed.

The Interim Policy on ECD recognises the need to provide services for children with disabilities and SEN and affirms the right of these children to become lifelong learners who will be active participants in society as a whole. However, there is as yet no indication of how this will be achieved.

The policy will guide the implementation of a national ECD pilot project which will initiate the start-up phase of the National Reception Year programme. The pilot project will explore the following areas:

- developing interim accreditation and standards for practitioners
- building provincial government and NGO capacity
- · developing interim policy
- establishing sustainable subsidies for community based ECD services. (Philpott, 1997)

## 2. Policy and legislation regarding special educational needs

The White Paper on Education and Training (1995) recognised the neglect of educational provision for pupils with special educational needs and proposed the appointment of a National Commission on Special Needs in Education and Training (NCSNET), which was appointed in January 1997. Together with the National Committee for Education Support Services (NCESS), it has a brief to make recommendations to the Minister of Education and Training (in October 1997) on all aspects of special needs in education and training. The Commission aims to consult widely, including with interested members of the public.

The South African Schools Bill is equivocal on the provision of SEN pending the outcome of the commission. There is provision for learners with SEN in the mainstream sector, but there is no **obligation** for the mainstream schools to accommodate such learners. Schools are cautioned to take into account the wishes of parents in the placement of children with disabilities and SEN. In addition, school principals cannot make decisions about admissions which conflict with the constitution by being discriminatory in nature. Parent organisations, such as Down's Syndrome South Africa, feel that this does not give parents enough leverage with reluctant principals, but await the outcome of the commission for direction in this regard.

## 3. Current situation of families of children with special educational needs

For children with disabilities, there is a minimal support structure. When disabilities are identified at birth, or by clinic nurses, the parents are given scant and often inaccurate information on what they can expect for their child. Rehabilitation services within the state hospitals are minimal. Physiotherapy and occupational therapy are available in all regions, but rehabilitation



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services are understaffed, lack equipment and urgently need more resources. The Department of Education provides pre-school programmes at a few special schools which are mostly residential. Very few of the special schools offer an outreach or home programme facility to children who are unable to attend the school. In the larger cities, such as Johannesburg or Cape Town, there are sophisticated services available to the more affluent families but, in the smaller towns, these services are not available to anyone.

In response to this situation, several NGOs and government-subsidised agencies have stepped into the gap. REHAB, an organisation providing rehabilitation and welfare services to individuals with different disabilities, runs a day-care centre and a home-help programme in East London, and reaches out to the rural areas. Many parents in the community have formed groups with the support of REHAB or the Disabled Children's Action Group (DiCAG). These groups provide day-care centres for children, and sometimes adults, with disabilities. The centres are run by mothers on a voluntary basis, and the Department of Welfare provides some funding for food and equipment. Many of the children in these centres have severe intellectual and physical disabilities; thus the centres tend to focus on the care of children, placing little or no emphasis on education or training. The Community and Child Development Centre also assists in raising awareness among teachers about including children with disabilities into their programmes and supports parents in placing their children in regular ECD programmes.

Mainstream placements are seen as a poor second to specialist schools. Some early intervention services are available but these are inadequate when children have severe disabilities. Where children with disabilities are integrated, both parents and teachers struggle to find ways of working with them in the mainstream setting.

In the wider community, attitudes towards children and individuals with disabilities are not very positive. In one of the courses we offer at CCDC, the following attitudes were reported by students from rural and peri-urban communities:

- parents have difficulty in accepting a child with a disability. The mother is often blamed for the disability and fathers deny responsibility for the child
- the child is not welcomed at school by either teachers or the other children and therefore feels isolated
- the abilities of persons with disabilities are underestimated and they cannot get jobs
- women and children with disabilities are subject to physical and sexual abuse; this is particularly

- true of children who are deaf or who have a mental disability
- concerned individuals recognise the problems in the community and tend to be over-protective or respond by 'making a school for these children': their attitude is one of pity.

## PROGRAMME DESIGN AND IMPLEMENTATION

The CCDC is a non-governmental organisation based in East London. Our purpose is to assist in the provision of education of the highest quality for all children. We aim to do this by providing training and support to ECD practitioners. Through this channel we aim to contribute to the development of the community as a whole. We believe in education without boundaries and therefore challenge the obstacles that presently exist, be they geographical, economic or attitudinal.

In 1993, CCDC recognised that in order to ensure that the needs of children with disabilities were being met, a specific focus on disability was needed. The aim was: 'to spread an awareness of the needs of children with disabilities and to promote their integration into society in general, especially through mainstream education'.

The following steps were taken to enable us to begin to implement this aim.

- The staff committed themselves to examining their own attitudes towards, and stereotypes of, people with disabilities. This in turn influenced the curriculum so that discussion of attitudes was included at all levels of training.
- Children with disabilities were admitted to the demonstration school attached to the CCDC, with a great deal of success.
- Trainers attended workshops on disability issues.
- The building in which we worked was made more accessible to wheelchair users.(Muthayan, 1994)

The positive experience of CCDC in addressing disability issues resulted in a growing commitment within the organisation to children with SEN, and the setting up of a project dedicated to promoting the inclusion of children with SEN into the mainstream of ECD.

A survey of learners enrolled at CCDC, which yielded the following results:

- negative attitudes in the community result in parents being reluctant to bring their children with disabilities to the local ECD centre for fear of ridicule and rejection
- lack of training on disability issues prevents
   ECD practitioners who are willing to accommodate all children from doing so
- under-resourcing of ECD centres, and the fact that most are not recognised or supported by government, makes inclusion difficult
- support from experts who can provide specific skills is lacking. (McKenzie, 1996).

The programme for inclusion was developed on the basis of these points. It has four components which operate together to create a holistic approach to the inclusion of children with SEN. The four components are:

- inclusion of children with special educational needs in the demonstration school attached to CCDC
- the development of special educational needs within training
- participation in policy development around ECD and SEN at a national and provincial level
- empowerment of parents of children with SEN.

## 1. Inclusion of children with SEN into the demonstration school

New Horizons pre-primary was set up by CCDC to serve as a model of a well-functioning ECD centre for the community-based centres. It is located on CCDC premises in East London and is presently subsidised by CCDC, but plans are under way to give parents more control and financial responsibility for the centre. There are two teachers at the school (one of whom is Montessori trained) and a teacher aide. The special needs consultant at CCDC supports the school with recruitment of children, assessment and adaptations to the curriculum for SEN.

#### Teachers and curriculum

The curriculum and teaching methods are Montessoribased, with the children playing a major role in designing their own programme for the day. We have found this helpful in an inclusive programme because children can proceed at their own pace. Peer learning is encouraged as one of the key elements of our inclusive approach. The teachers at New Horizons have taken on the challenges of inclusion in a positive way. They aim for maximum inclusion and seek technical advice, which the special needs consultant will access for them, when they cannot achieve this. They report that they have learnt from having children with disabilities in their programme and that they feel they are making a valuable contribution by meeting the educational needs of all children.

## Teacher aides

The inclusion of a child with a severe physical disability has necessitated the employment of a teacher aide who has responsibility for certain tasks with all the children, under the guidance of the teacher. She also has a specific responsibility for the children with disabilities. The aide has received specialist training in positioning and exercises for the children in her care. It is also worth noting that she is a person who went through special schooling herself and who has found her first job with us.

### Specialised equipment

While it is true that inclusion of many children with disabilities into the mainstream can be achieved at very little additional cost, some children require specialised equipment. We received a donation of approximately US\$1200 for equipment and with this we were able to buy sufficient equipment to accommodate learners with severe physical disabilities. An alternative would be to borrow the equipment from the rehabilitation services or to make equipment using low-cost techniques. The equipment facilitates a disabled child's independence and we feel very strongly that it is an essential part of inclusion.

### Pupil response

We have been impressed by the ease with which the more able children assist and support the others. Through observation we have noted that an assertive personality is a great asset for the child with severe disabilities in a mainstream setting, because it is ultimately up to the child to control how much help he or she needs and what he or she can do independently. It is the task of those without disabilities to learn to respect these guidelines and to respond accordingly. For some children this can be difficult – there are those who persist in patronising the children with disabilities and others who ignore them, thus reflecting the range of responses that can be expected from the wider community. We attempt to demonstrate more appropriate interactions by relating to all the children in the same way.

## Impact of the project

Since the programme started, six children with disabilities have passed through the centre. This is a very small number and the impact can be no more than minimal if we do not disseminate our experi-



ences. We have to be able to show that inclusion can and does work, even on a small scale. Thus the school is open for observation by students and interested members of the public. We have had media coverage of the school which has also raised questions around inclusion.

## Moving into formal education

A major issue is what happens to the children when they leave our programme. We have not yet successfully 'mainstreamed' any of them. This could be because of the strength of the special school model within our community, combined with the inadequacy of mainstream schools. We are caught in a dilemma: special school placements are often in the best interests of the child, as the mainstream education sector is generally hostile towards children with disabilities being educated in mainstream schools. On the other hand, long-term change within mainstream education is probably only likely to occur through pressure, which will inevitably come from parents who are willing to take on such a challenge, as has been the case in the United Kingdom and the USA.

## 2. Special educational needs within training

The people who come for training at CCDC are, in the main, local women who have identified the need for child care in their communities and have decided to learn more about how they can provide this service. Many of them are volunteers who receive little or no remuneration for the many dedicated hours they put into this work.

### 'Weaving' inclusion into the curriculum

This aspect of the programme is staffed partly by the special needs consultant and partly by a community 'educare' developer or trainer. CCDC believes that training for inclusion should not be seen as distinct from general training. Teaching children with disabilities or other special educational needs is not a special skill, or an additional one, but an integral part of what a teacher does in the classroom. By 'weaving' aspects of special educational needs into a curriculum which promotes a child-centred approach, we aimed to instill within our trainees a sense of responsibility towards children with disabilities and some basic skills in accommodating them within the mainstream classroom.

The early identification of disability is included in our first level of training. Trainees are continually required to devise adaptations for children with physical, mental or sensory disabilities to encourage their full participation.

In order to ensure that this occurs throughout training, we have held 'training the trainers' workshops on disability issues. These workshops have revealed that, given the right attitudes, the aims can be achieved. Generally, trainers are committed to an inclusive approach and only need technical support.

#### Short course

We also offer a short course on the inclusion of children with special educational needs into ECD, set up in response to a demand for training for students not currently in training at CCDC. By the end of the course, the trainee should be able to:

- understand the reasons for an inclusive approach and why this approach is being adopted nationally and internationally (knowledge)
- develop positive attitudes in her/himself toward disability and towards inclusion specifically (attitudes)
- include children with disabilities in the classroom (skills).

Our first course was held in May/June 1996 for 29 students. Their response was very enthusiastic, as shown by their comments.

'Well planned. Information might help community to accept disabled people and to accept their rights.'

'What was helpful to me was in overcoming the fear I had in inclusion of disabled kids in the community as well as in the class. Inclusion to me was a dream.'

The course has a student manual and a manual for the trainers. The course includes guidance on how to make equipment from natural or waste products which would be suitable for all children. We continue to run this course centrally and are now working on taking this training out into rural communities.

As a follow-up to the courses, we have conducted community visits. We have detected a greater willingness for teachers to accept children with disabilities but a lack of skills to ensure that they are fully included in all classroom activities. We now recognise that teaching methods and curricular considerations must form a larger part of our further training.

## 3. Input into policy development

As was pointed out in the introductory section, South Africa is in the process of implementing major changes in its education system. We believe that we should not wait for policies to be formulated but that we must participate in policy formulation so that SEN is an integral part of the overall process. Since inclusion is a relatively new concept in the country, this needs to be advocated in all possible fora. Our involvement in policy operates at a national, provincial and regional level.

#### The national level

We are involved in the South African Federal Council on Disability Education Working Group which has had a major input into the processes of setting up the national commission. Several members of this group have subsequently been appointed to the commission and we are therefore able to keep abreast of developments. We have also linked with UNESCO through this group. We had the privilege of assisting DPSA in organising a national workshop on inclusion within ECD in 1995 and this has formed the basis of a network of interested people.

## The provincial level

While there is much progressive thinking at the national level, this is not always reflected provincially, where the executive powers for the provision of education lie. We were therefore pleased to be able to participate in the development of a provincial curriculum framework for ECD. A curriculum committee developed a curriculum framework that places the inclusion of children with SEN squarely within its scope. Recommendations as to how this can be achieved are included in the document which will be distributed to every school in the province as the official guidelines for ECD. Perhaps the most significant aspect of the curriculum is that it achieves this inclusive approach by adhering to national policies. An outcomes-based approach which fosters positive attitudes to diversity and which has a child-centred core encourages teachers to look at each child as an individual, rather than as a label, and therefore facilitates the process of inclusion.

### The regional level

We have established a small education working group with SAFCD affiliates in the region: Down's Syndrome Association, Disabled People South Africa,

Societies for the Blind, Mental Health and Physically Disabled, with some input from the Society for the Deaf. This group came together to formulate a joint submission to the NCSNET and NCESS and to formulate a combined presentation for a department of education conference on inclusion. We anticipate that this group will continue with the aims of providing a voice for parents of children with SEN, individuals with disabilities and NGOs and service providers, particularly in negotiations with the Department of Education. In addition, it will provide a body to advocate for children with SEN and to develop expertise in this area throughout the region. We are in the process of inviting other organisations in the province to form similar groups and to work with us on issues of mutual concern.

## 4. Parent empowerment

Initially our strategy was to work with parents of children attending the demonstration school, but this was not very successful. This necessitated singling them out from other parents, which we did not want to do. We were also assuming that they had issues in common with each other, which they might not have perceived or agreed with. We found that parents have little time for additional participation that does not directly meet their needs.

In considering these issues, we have concluded that our role at CCDC is to support parent information, support and advocacy groups which are achieving parent empowerment. We have taken an active role in the development of a local Down's Syndrome Association and liaise with the Disabled Children's Action Group which falls under Disabled People South Africa and which is active in the rural areas.

## 5. Other aspects of the project

#### Outreach

We have recently been invited by a rural district committee to assist them with setting up a community child-care centre. We have taken this opportunity to introduce a philosophy of inclusion which is relatively new in such areas and has met with some resistance. We hope that through mutual respect and working together we will be able to influence thinking in this district.

On an informal basis we act as an advice and advocacy centre to parents who are experiencing obstacles to accessing education for their children with SEN.

We have offered training to visitors from Lesotho and we are busy negotiating to work with a community health worker training project in a nearby rural community.

## **Funding**

We have received some funding specifically for the inclusion project but much of the work we do is supported by the centre as a whole and does not require independent funding. For example, our involvement in curriculum development is ongoing and forms part of the overall running of the CCDC.

## Staff training

This is ongoing but problematic. We are not able to access any good training on the inclusion of children with disabilities and curriculum development in South Africa. Much of the existing training is based on a medical model of disability, which is inappropriate for our needs. We hope to visit other countries which are more advanced in this respect to learn from their work. Staff have, however, had the opportunity to develop their general skills in working with children within the Montessori approach.

#### Networks and collaboration

Collaboration and networks are also crucial in our work, and our partnerships include: the two major hospitals which identify children with disabilities; the Association for the Rehabilitation of Persons with Disabilities (REHAB); Disabled People South Africa (DPSA); and the Disabled Children's Action Groups (DiCAG).

## PROBLEMS AND MAJOR ISSUES

#### 1. Attitudes

In South Africa we were exposed to a racially-segregated educational policy in the apartheid years. We are now working very hard to overcome this fragmentation and to build a unitary system. However, many people retain the apartheid mind set when it comes to children with special educational needs, believing that it is necessary to maintain a separate system of education for such children. There is a sense that we do not value the potential of our learners with disabilities and other special educational needs as much as we value the typically developing child. In a recent conversation with parents of children with Down's Syndrome, parents expressed their frustration with the low expectations placed on their children. There is a clear need for demonstration schools or pilot projects which will make the idea of inclusion a reality.

Children are not taught from an early age to respect individuals with disabilities and teasing and abuse are generally more common than supportive behaviour. The disability rights movement, under the leadership of Disabled People South Africa, has made some progress but we still have a long way to go. We believe that the ECD sector also has a major contribution to make in nurturing positive attitudes about individual differences in children.

## 2. The education system

Stress within the education system

For the majority of children in South Africa, education takes place within under-resourced classrooms, with a high pupil/teacher ratio and a rigid curriculum. Teachers are under pressure to get through the syllabus and to ensure that all pupils are able to perform according to given standards. Since the advent of democracy in South Africa, education has been through a period of transition, with the creation of a totally new system. This has put educators under a great deal of stress and pushed them to the limits of their capacity for change. In addition, there is a mistaken belief that SEN affect a small number of children and that educators must keep their vision focused on the needs of the majority. These factors have created a negative attitude towards inclusion. However, we have adopted the view put forward by Villa and Thousand (1992), and others, that an

inclusive educational setting which meets the needs of children with SEN will be good for all children.

### Out-of-school children

Children with multiple disabilities, severe mental handicap, mild mental handicap and homeless children are particularly severely affected by exclusion from the education system. The DiCAG centres only scratch the surface of this problem and in our view are a crisis response to the problem rather than a real solution. We hope that by including these children within ECD programmes, the awareness of their needs and of their potential will be raised and the need for education for ALL children highlighted.

A person with a disability is traditionally seen as the responsibility of the Welfare Department. This is particularly true in the rural areas, where grants for young children and adults with disabilities are highly sought after as a source of family income. While accepting the need for these grants, it is unfortunate that this helping mechanism has tended to create an attitude of dependency. Children who are excluded from mainstream or special schools (usually because of the severity of the disability) receive no support from the Department of Education, but their families receive a grant from the Department of Welfare. The Department of Welfare also subsidises day-care centres which provide a valuable caring service but rarely offer an educational programme. It is our feeling that children of school age should have their educational needs met by the Department of Education, rather than the Welfare services. Our constitution guarantees the right of all children to an education and we are hoping to mobilise parents and politicians to lobby, even to the point of taking the Province to the Constitutional Court.

## Inclusion versus special schools

There is a tendency for discussion of the provision for special educational needs to polarise around the issues of inclusion versus segregated education. We believe that this is an irrelevant issue, as neither the special schools nor the mainstream schools can currently lay claim to meeting the real needs of children with SEN. We need to try to work out how to meet these needs, regardless of the setting in which the children are placed.

Within specialist schools there is often animosity toward the concept of inclusion, perhaps because it is threatening to professionals who are comfortable with a certain way of operating. While it is clear that there will be a more inclusive approach in the future, there seems to be agreement that special schools are here to stay.

SOUTH AFRICA

Many of the special schools accept children with fairly mild disabilities (for example, post-polio) and reject children with severe disabilities. We believe that this needs to change, so that special schools provide support to children with disabilities in the mainstream and take responsibility for educating the children with more severe disabilities in the special school setting.

## 3. Inadequate rehabilitation and health services

Many children with disabilities receive no form of intervention until they enrol in a school or the ECD programme. By this stage, parents' expectations are low and many children have developed maladaptive behaviour. It then becomes logical for schools to refuse these children admission on the grounds that they are disruptive or show little potential for learning. Early intervention services are vital, but these need to be inclusive from the start. Parents need to understand that for their child to be included in the education system, they must first be fully included within the family. Collaboration between health and education is necessary to send the same message to parents: that of integration within society.

## 4. Working from a non-governmental organisation

As an NGO, our impact is largely in the informal education sector. It is not always easy to impact on government, which is obviously the major provider of education. We are fully aware that the development of inclusive ECD centres should be followed up by inclusive primary schools, but this is not happening. We have adopted a two-pronged approach to addressing this issue. The one is to work on a policy level, from the top-down, and the other is to work with individual schools in a bottom-up approach. The latter is difficult because schools are fairly closed systems which like to protect their autonomy. We hope to work on this aspect by setting up a pilot project which formalises the relationship between our centre, parents, schools and support services.

### 5. Limited resources

Our programme runs on a budget of approximately US\$20,000 per year. We have had to confine ourselves to small interventions which we hope will have a long-term impact. However, with growing experience and confidence in our work and increased demands for our services, we envisage the need for expansion of the project. We are experienced enough

to offer training in inclusive education to ECD practitioners from a wide range of settings, but we would need to develop more staff to do this on a large scale.

## LESSONS LEARNED AND CONCLUSIONS

#### 1. Attitudes

First and foremost, inclusion is about attitudes. Inclusion begins with parents. Parents who accept and love their child, and who are prepared to allow the child to develop his or her own sense of worth and identity, will provide the necessary support for what is often a difficult and demanding process in the mainstream sector. For inclusion to become a reality, we need to expect that children will achieve their potential. We have seen successful inclusion occurring in poverty-stricken environments where teachers have little formal training but understand the potential within the child, and strive to release it.

### 2. The curriculum

We remain opposed to cosmetic inclusion where the child with SEN is placed in a mainstream classroom as a token gesture. Within a rigid curriculum, this is often the case. There must be room within the curriculum for different ability levels and individual goals. Villa and Thousand (1992) review some of the curricular tools that enhance learning for all children, such as co-operative learning and peer tutoring. We hope that by moving toward an outcomes-based approach in education in South Africa, there will be more room for curricular innovations which will benefit not only learners with SEN, but all learners.

### 3. Support of the organisation

Probably our greatest strength at CCDC has been the support of the whole organisation for inclusion. While we are identified as one particular centre project, the centre as a whole is fully supportive of the approach. We are fortunate in that we do not have to fight to make ourselves heard, but that inclusion is an attitude that the entire organisation prides itself on.

### 4. A holistic approach

The project described above has managed to have a far-reaching impact from small beginnings. We feel that this is because we have adopted a holistic approach. We do not feel it is enough just to train teachers or to work on research and policy development. To have a real impact, all the components of the project need to work in a complementary way.

### 5. Parent participation

We have developed parental participation and involvement in deciding what they want for their child by presenting them with the alternatives and helping them to work out what is best for them. In a transitional education system which is not prepared for children with SEN, parents need to be committed to the path that they have taken and need intensive support from other parents and professionals.

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# Inclusion for Pre-School Age Children: A Collaborative Services Model

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### INTRODUCTION

Recently, there has been a consensus on the need to redefine the relationship between early childhood special education and early childhood programmes. This stems from a growing body of literature on the educational benefits of including children with disabilities within programmes for children who do not have disabilities. As a result, the major professional organisation for early intervention in the United States, the Division for Early Childhood of the Council for Exceptional Children, has adopted a position paper supporting inclusion.

Inclusion has been cited as a quality indicator of early childhood intervention, and a number of recent service delivery developments in early childhood intervention are contributing to the continued expansion of inclusive programmes. These are as follows:

- Families have become increasingly vocal about their expectations for their children with disabilities.
- There has been an increasing demand for child-care services for young children. More than 11 million pre-school children attend early care or school programmes.
- The Individuals with Disabilities Education Act has emphasised the rights of eligible infants, toddlers and pre-school aged children to receive early childhood intervention services within 'natural environments'.
- The Americans with Disabilities Act prohibits discrimination against individuals with disabilities

by state and local governments and public accommodations. All state and local government operated services for children, such as child-care centres, pre-schools, park, recreation and library services cannot exclude from participation in, or deny the benefits of, their services, programmes or activities, or otherwise discriminate against a child with disabilities. Moreover, the United States Department of Justice states: 'Integration of individuals with disabilities into the mainstream of society is fundamental to the purposes of the Americans with Disabilities Act'.

- In early 1993, the Administration for Children and Families within the Department of Health and Human Services established rules which set performance standards for children with disabilities in the Head Start Programme (early childhood programme for low income children and families).
- Young children aged three to five who are eligible for special education and related services have the right to receive these services in inclusive environments. This was established in two memoranda which were issued by the Office of Special Education and Rehabilitation Services, of the United States Department of Education. Use of both private and public programmes (such as Head Start) for non-special needs children and as special education placements for children with disabilities is one strategy which has been identified to ensure that the setting is not restrictive.

In addition to the expansion of inclusionary early childhood opportunities, the growing population of children 'at-risk' for disability because of biological or environmental factors has called attention to the need to increase the availability of quality early

education programmes for all young children. These two service delivery trends, inclusion and a growing population of at risk children, have provided an opportunity to design collaborative early care and education models which encompass all young children, regardless of a child's specific needs or label.

### A COLLABORATIVE EARLY CHILDHOOD SERVICE MODEL

The Collaborative Services Project is a five-year model demonstration project funded by the Early Education Programme for Young Children with Disabilities, U.S. Department of Education. The project represents a collaborative effort between the University of Connecticut School of Medicine, Department of Pediatrics (UCONN), Hartford Public Schools, Hartford City Day Care and Hartford Head Start. These programmes serve approximately 1200 children who have disabilities, are at risk for disability, or are typically developing.

### 1. Project location

Hartford's population is 139,740 and it has the lowest per capita income in Connecticut, with 25% of residents living below poverty levels. Seventy percent of Hartford's population is 'minority', about equally divided between African Americans and Hispanics. Hartford's Hispanic population has experienced remarkable growth, and 60% of children under five are Hispanic. The public school system is 93% 'minority'; 43% African American and 45% Hispanic. Most Hispanics in Hartford (up to 90%) are Puerto Rican.

Fifty-seven percent of all Hartford children live in low-income single parent households; 18% require special education services; 45% come from a home where a language other than English is spoken.

As Hartford's economy worsens, indicators of human need continue to rise. The number of Hartford residents who are HIV-positive more than doubles each year and the number of babies born with special needs due to maternal drug use escalates. Infant mortality rates, the percentage of low-weight births, and the percentage of births to teenage mothers are among the highest in the United States. The annual number of births grew by 20% in the last decade.

The Hartford Public School system (HPS) enrols 26,400 students. HPS enrols 4% of Connecticut's public school students, but has 40% of its bilingual population and 16% of its special education students. Unfortunately, HPS is only serving a portion of those eligible for special education at the pre-school level. The most recent data suggest that only 1.6% (51 children) of 3 year olds and 3% (90 children) of 4 year olds were receiving services.

### 2. Project design

The purpose of the project is to develop, implement and evaluate a model of collaborative and inclusive early childhood services within an urban school district for young children with disabilities and their families. Three types of collaboration are emphasised:

- Inter-agency collaborations, to assist in policy development for both local and state-wide planning.
- Service delivery collaborations focus on the adoption of recommended early childhood intervention practices within the public (state) schools' pre-school special education programme, the Head Start programme, and the day-care programmes.
- Family collaborations focus on the adoption of policies and practices to increase the involvement of families across early childhood programmes.

The ultimate goal should be the collaborative development of an individual education plan (IEP) carried out under the direction of the family.

The main elements of the project are shown on Figure 1.

# 3. Component one: inter-agency collaboration

It is clear that few agencies have the resources to provide a total continuum of services which encompasses all the issues that may impinge upon a young child with disabilities and his or her family. Therefore, agencies, programmes and staff must be prepared to co-operate and collaborate for the benefit of families. For example, a child of Puerto Rican heritage who was prenatally exposed to drugs requires the expertise and services of bilingual early intervention staff, medical staff and community agency staff.

There is no magic formula for developing collaborative models, but a number of key ingredients have been identified; in particular, Melaville and Blank (1991) have identified five variables which shape an effective inter-agency collaborative system.

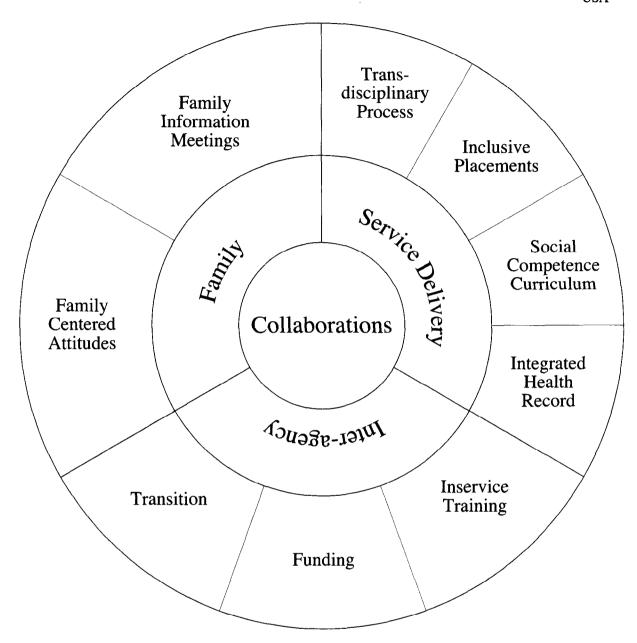


Figure 1: Project Component and Elements

## The social and political climate for change

A more favourable climate for collaboration occurs when the targeted service delivery issue is a priority for each of the service agencies. However, not all participating agencies may agree about what needs changing. For example, they may not agree on the necessity for service improvement. However, it seems clear that the multiple needs of children and families have created the need to prioritise collaboration, and this should facilitate the development of a favourable climate in which change can occur.

# The processes used for communication and problem-solving

Inter-agency collaborations rely on the adoption of a process to establish goals and objectives, clarify roles, make decisions and resolve conflicts. The first step is the adoption of a common vision by all involved in the service delivery system. Difficulties in the establishment of a vision across the relevant agencies and programmes stem from differing interpretations about the adequacy of the existing system. Resolution can only occur when specific processes are agreed upon and adopted by all participants to ensure open, continued communication, negotiation and conflict management.

### The human dimension

The people involved in the creation, development and implementation of the inter-agency service system are a critical factor in the ultimate success of the collaborative model. An effective leader who can establish, and help sell, the vision to all participants is essential. He or she must also be able to translate the vision into the reality of service delivery. The commitment of the other participants, at both policy-making and service-delivery levels, is also vital. All should have access to support and training as their roles change with the development and delivery of a collaborative service delivery system.

### The policies which support or inhibit inter-agency collaboration

Each participating agency and programme entering into an inter-agency collaboration has a set of rules and regulations which governs their mandate, target population, budgetary operations and service structure (including staffing patterns). Agencies and programmes must be prepared to identify and share these policies with each other so that barriers to interdependent functioning can be identified and removed.

### The availability of resources

In an age of shrinking resources, inter-agency collaborations are often the only way to guarantee the development of an integrated service system. Early childhood intervention is one area in which resources must be pooled to ensure the development and delivery of services.

A collaborative climate must be maintained during the inter-agency process, and all agencies must feel free to contribute issues and solutions which are then jointly resolved. It is important to maintain a positive atmosphere of communication and trust among the participants which is more easily achieved when the focus of the collaboration is on the people involved, rather then the individual agency and programme requirements. This focus should include both the consumers of the services (families and children) as well as the service providers. The collaborative vision can be defined as 'relationship driven', as the participants focus on improving the services or system for children as opposed to agencies and programmes.

### 4. Component two: service delivery collaborations

While programme development hinges on the effectiveness of inter-agency collaborations, the actual service delivery must be implemented by individual service providers. The personnel will have to adopt a team model to ensure collaborative service delivery and the success of the interventions will be dependent on the way the team functions. Teams must devote time to identifying their goals and objectives. A truly effective team exists when members share responsibility for accomplishing common goals. An effective team will:

- have goals which are clearly understood, and communicated to all team members
- have ownership of the goals and participate in setting them
- have goals which are operationally defined and measurable
- share individual or personal objectives with one another.

This project deploys a cross-disciplinary team, which is one that functions around the needs of the family as opposed to the needs of discipline-specific service providers. The members share roles and systematically cross disciplinary boundaries in accordance with the assessment or service delivery needs of the family. This involves continuous give and take between all the members of the team (especially the family) on a regular, planned basis. Assessment, intervention, and evaluation are carried out jointly by designated members of the team.

As with effective inter-agency service delivery models, collaboration is inherent in the cross-disciplinary team approach. A cross-disciplinary team is one in which the members perceive that they can obtain their own goal if, and only if, the other team members also obtain their respective goals.

In order to facilitate service delivery collaborations, this component focusses on team process, recommended practices in inclusion, the development of a social competence curriculum and the use of individual health care plans for eligible children.

# 5. Component three: family-centred collaborations

Parents of a young child with disabilities are rarely prepared for the special challenges they will face. Most parents report an increase in the level of stress they perceive as a result of the birth of a child, but the parents of a young child with multiple or severe disabilities must deal with unanticipated pressures

and responsibilities which can make the parenting role appear to be overwhelming.

An expanded focus on family systems theory has resulted in the recommendation that early intervention programmes move away from the narrow focus of the child and encompass the broader and self-identified needs of the enrolled parents. It has been suggested that the primary goal of early intervention should be to facilitate the parents' awareness of, and adaptation to, the primary role of parenting a child with disabilities. A programme can then focus on helping the family address the long-term needs of their child. The project has a particular focus on family support strategies.

A recent suggestion has been for early intervention programmes to recognise the ongoing stress that parents of delayed and at-risk young children may be experiencing by helping families adapt to stress through the recruitment of support networks.

It has been suggested that both formal and informal support strategies should be integral to any service delivery system for families with high-risk or disabled children. The support strategies should be both formal (e.g. assistance with insurance and financial needs: identification of respite services; training on medical equipment) and informal (e.g. identifying existing community resources; facilitating family involvement within the school). The overriding premise of such support is that it must be individually matched to the needs of the family, and the use of such strategies should be directed by the family. These principles have been articulated as components of family-centred care and these are listed below. 'Family-centred care' suggests that all services revolve around the family as it is the family which will be the constant in the child's life.

### Principles of family-centred care

- a) Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
- b) Facilitation of parent and professional collaboration at all levels of health care.
- c) Sharing of unbiased, complete information with the parents about their child's care on an ongoing basis and in an appropriate and supportive manner.
- d) Implementation of policies and programmes that are comprehensive and provide emotional and financial support to meet the needs of the family.
- e) Recognition of family strengths and individuality and respect for different methods of coping.
- f) Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems.

- g) Encouragement and facilitation of parent-to-parent support.
- h) Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs.

### PROJECT IMPLEMENTATION

### 1. Project participants

The HPS serves approximately 120 children with disabilities, aged three to six. There are 19 early childhood special education classroom teachers, assigned to 30 classes at 25 sites (separate morning and afternoon sessions). Seven additional peripatetic teachers provide services to pre-school children with disabilities placed in other programmes throughout Hartford. The HPS also has 11 speech, language and hearing pathologists who provide services to children identified as having disabilities.

Hartford City Day Care serves a total of 274 children at eight centres in Hartford. There is a staff of 52 teachers and assistant teachers working with children of up to kindergarten age.

Head Start serves approximately 860 children at 13 different sites throughout Hartford. Ninety teachers and assistant teachers provide services to pre-school children aged three to five. In accordance with mandated federal guidelines, a minimum of 10% of the enrolment has been assessed as needing special education services through the HPS. Peripatetic teachers and assigned therapists provide related services to the children with disabilities who have individual education programmes at the Head Start sites.

### 2. The project in action

During the first three years of the programme, all teachers across the agencies participated in every aspect of the project through training workshops and focus groups. In addition, specific child-focussed activities were implemented in different classrooms throughout Hartford. Forty-three children with disabilities were placed in inclusionary early childhood classrooms, and 142 additional children with disabilities received technical assistance in order to remain in inclusionary placements.

During the first year of the project, the model development process was initiated in one school within the

Table 1 **Evaluation strategies** 

|                                | Observations | Meeting<br>Minutes | Agendas | Intervention<br>Plans | Surveys | Interviews |
|--------------------------------|--------------|--------------------|---------|-----------------------|---------|------------|
| Interagency                    |              |                    |         |                       |         |            |
| transitions                    |              | X                  | X       |                       |         | x          |
| funding                        |              | X                  |         |                       |         |            |
| inservice training             | X            |                    | X       |                       | X       |            |
| Service Delivery               |              |                    |         |                       |         |            |
| inclusive placements           | X            | X                  | X       | X                     | X       | X          |
| transdisciplinary curriculum   | X            | X                  | x       | X                     | X       | X          |
| social competency curriculum   | n x          | X                  | x       | X                     |         | x          |
| integrated health care records | 3            | X                  | X       |                       |         | X          |
| Family                         |              | , m. s.            |         |                       |         |            |
| parent meetings                | X            | x                  | X       |                       |         |            |
| staff attitudes and activities | X            |                    | x       |                       |         | X          |

district. This school contained three early childhood special education classrooms (total enrolment of 23 children); a diagnostic play group for three-year-old children with disabilities; and other early childhood programmes which included two Head Start classes; one kindergarten 'readiness' class; four kindergarten classes; and a daycare classroom. Staff from each of these programmes participated in training and received technical assistance.

The model expanded in the second year of the project to include another school within the district. This school contained three early childhood special education and two pre-kindergarten 'readiness' classes. During the third year of the project, the team-teaching model was replicated in a daycare class housed in a third elementary school. An early childhood special education teacher and six pre-schoolers who had disabilities were also assigned to the daycare class. During the current and fourth year of the project, a kindergarten using a team-teaching approach is being added in Hartford, and two other school districts in Connecticut will participate in the project.

# PROJECT EVALUATION METHODOLOGY

Given the high volume of activities proposed in this project, it was imperative that a systematic and detailed plan of evaluation was developed. Such a plan allows for regular and frequent input from consumers and professionals regarding the direction of the project, in order to assure that the activities are functional to the field, socially relevant and scientifically sound. As such, both formative and summative evaluations are being conducted on both process and product outcomes.

The evaluation plan consists primarily of an objective or goal-based approach to evaluation. Multiple measures of effects are used whenever possible to document outcomes. In addition, family and child measures are used to document the effectiveness of implementation and replication objectives, particularly within the service delivery component. Whenever possible, statistical analyses are used to document project outcomes across training audiences and consumers (families and children).

Case-study methodology is also being used to gather qualitative information from families and children, and agencies are participating in the project.

Table 1 provides an overview of the sources of data that were used to complete the case study.

Table 2 **Training topics and workbook topics** 

| Training Modules                                            | Workbook Topics                                       |  |
|-------------------------------------------------------------|-------------------------------------------------------|--|
| Developmentally Appropriate Practice                        | Inclusion                                             |  |
| Team Work                                                   | Classroom Management                                  |  |
| The Changing Role of the Assistant teacher in the Classroom | Curriculum Adaptation                                 |  |
| IEP Development and Implementation                          | Glossary                                              |  |
| Behaviour Management                                        | Routine Based IEP                                     |  |
| Play and Play Intervention                                  | Social Competence                                     |  |
| Attention Deficit Disorder With and Without Hyperactivity   | Transdisciplinary Teaming in the Pre-school Classroom |  |
| Social Competence                                           |                                                       |  |

### PRELIMINARY RESULTS

### 1. Inter-agency collaborations

The focus of the inter-agency component is to identify common goals across the three agencies of Hartford Public Schools (pre-school special education), Hartford Day Care and Hartford Head Start. Approximately 25 three-hour meetings were held during the first three years of the project which were attended by the directors of the three programmes. During these meetings both philosophical and logistical issues were discussed.

The project's goal of inter-agency collaboration was not easy. The agencies had no experience of cooperating with each other, and they differed in their perspectives on early education and their mission for children and families. All three agencies were pleased about receiving assistance from the project, but they were not really clear on the collaborative emphasis of the project. To them, collaboration was an end goal in itself as opposed to a means to an end. Although the interpersonal relationships between the programme directors were cordial and respectful, the organisational relationships and perceptions were more critical, as documented through interviews at the beginning of the project. The agencies had differing priorities and perceptions of good practice which meant that relations were sometimes strained.

During the three years, the directors' meetings focussed on the direct implementation of project goals. The meetings also provided the time for the individual programme directors to get to know each other. After three years, the programme directors have built good working relationships, as evidenced by an interagency agreement between the public schools and Head Start, and the continuation of monthly meetings as requested by them. These monthly meetings provided the opportunity to discuss the individual model elements within this component: training, transitions; and funding.

### Training

There was a clear consensus that more training and more support were needed by the teachers in the project. During the first three years of the project, 189 teachers (across agencies) participated in 56 training sessions covering 28 topics. Detailed training syllabi were designed for 10 of the topics and participants' workbooks completed for eight topics.

The training occurred at convenient times for the participants, and included participatory strategies and applications to classroom situations. Pre- and post-questionnaires on training content suggested significant gains in knowledge.

Comments about the training which were given during interviews with teachers were overwhelmingly positive. One teacher said: 'Before the training

I hated inclusion. I felt it would be another strain on the teachers. After the training, reading information on inclusion, I felt that children with disabilities deserve to be included in every learning process with the typical (quote, unquote) child!'

The administrative team also valued the training as evidenced by a comment by the Head Start administrator. 'I know we have some people in the programme who are capable of helping others better, but we just need to form a sort of team and sort of steer them through it [the process]. I'd like a training team because in each centre, I can see at least four people who have already done workshops, who understand the techniques, who could easily train or assist in helping the new staff coming in'.

### **Transitions**

All three agencies agreed that the transition process for children with special needs was seriously flawed. There was also consensus that a smooth transition process is important. The uncertainty of placement decisions was one of the basic problems. As one teacher stated: 'Even now [June] I can't even tell parents where their kids are going.'

Another issue was raised by the Public School director who indicated that among the many transitions (birth to three into the system; pre-school into kindergarten; and between more or less restrictive environments) she felt the most difficult transitions were between special and mainstream education classes.

Almost all the comments about the transition process were made by the Public School teachers and administration. Only one comment was made by someone from another agency: a representative from the Day Care services indicated that participation in the project made her more conscious that 'the children will be leaving' and of the need for transition planning.

As part of the project, a regional transition task force was developed to address all the transition points for children with disabilities. Twenty-six agencies participated and the result was the adoption of a common set of guidelines for parents of children with disabilities, from birth to the age of eight. This occurred during the third year of the project, and it will be implemented during the fourth year.

### **Funding**

This area remained the most problematic and, as a result, very little was accomplished. During the first year of the project a private education agency, Education Alternatives Incorporated (EAI), was given the responsibility of running the HPS in an effort to reduce costs; EAI lasted three years but was then voted out of Hartford by the School Board in February of the project's third year. EAI controlled budget decisions, and did not include plans for children under the age of six in any planning. The public schools' pre-school budget remained stable during this time. Unfortunately, Head Start and Day Care services continued to lose funding as the Hartford economy worsened. Funding is a very important issue, and one which the agencies do not want to share, as their focus remains on their own survival.

### 2. Service delivery collaborations

'Frankly, it's hard to collaborate'. That was a comment made by one of the pre-school special education teachers involved in the project, but it serves as a summary statement for the comments made by many of the teachers providing services across the agencies. The barriers to collaboration were evident: the lack of time to meet and plan joint efforts, the lack of information-sharing between agencies and the less than positive attitudes some participants showed towards the policies and practices of the other agencies.

Several of the teachers indicated that they felt collaborative bonds had been established between their agency and the project staff at UCONN, but that they did not feel connected to the other agencies. 'I feel like we're all like kind of little separate entities that are together but not really. I mean, it's like we're collaborating with you, they're collaborating with you, but we're not collaborating together'. One of the other respondents identified collaboration as a goal of the project but not a goal he shared; his goal was focussed more on improving his classroom and agency. The four elements under this component each presented separate challenges.

### **Teaming**

The concept of teams of professionals working together co-operatively (if not in a full cross-disciplinary model), however, was well supported. Several of the Public School teachers suggested that cooperation between professionals was required for good early childhood practice is a collaboration between the adults in the room,

between adults in a building, such as your resource people who you can call upon when you're stuck on a problem... the nurse's office... the speech people'.

The usual barriers of insufficient time and resources for teams were also well documented in the discussions. In the Hartford system, there are few occupational and physical therapists, and few speech and language specialists. To try to overcome these barriers, some teachers expressed a desire to set aside specific meeting times so the group of professionals working with a child could get together to 'help with problems, being able to talk problems out.'

The difficulty of getting the level of support desired was echoed by the Public School administrator involved with special services. 'We are trying to facilitate more collaboration between our staff... but I don't feel... I can give them the constant support on a regular basis because of the heavy schedule'.

During the three years it was found that the use of a consistent planning time and process with the involved individuals could create a climate for collaborative teaming. The most difficult issue concerned roles and responsibilities, particularly those for the special education teacher. As the Day Care Senior Teacher indicated: 'I think team teaching is very difficult and... {the} special education teacher and I haven't quite worked out what our relationship is.' The special education teacher also expressed difficulties, 'I had a hard time myself. Just, you know, trying to figure out what my role is here in the centre.'

Recognising the importance of clear roles and responsibilities, the project facilitated team meetings in a number of collaborative sites. The focus of these meetings was role clarification and programme planning for the children with special needs. Of most concern was that such meetings were not a formal and mandatory part of the process. After the third year of the project, Day Care and the Public Schools agreed to mandate weekly team meetings at all of the inclusive sites.

### Inclusion

At the beginning of the project, most of the teaching staff across the agencies did not have much experience with inclusion. Head Start, by federal mandate, had a policy requiring that ten percent of the children it served had to be children with special needs. Thus, several of the teachers at Head Start had had some exposure to children with special needs. However, as explained by both the teachers and administration at Head Start, most of the children's special needs were speech and hearing related; fewer had motor or physical disabilities.

During the three years of the project, 43 children with moderate to severe disabilities participated in inclusive classrooms facilitated by project staff. An additional 142 children who had IEPs were provided with technical assistance by the project staff in order to enhance their intervention and participation in inclusive settings. The participating teachers all felt the benefits of this. As one teacher said: 'Inclusion is a great start for young children with special needs. They have the opportunity to interact with children who have no disabilities. Inclusion helps the young child with his self esteem, which is very important in a child's early years.' Another believed that: 'Children with special needs should be included in a "regular" classroom whenever possible. It helps the children in the classroom be more accepting and understanding of children and people with disabilities. It also helps the disabled children feel accepted and a part of a regular group. They can learn positive normal behaviours from other children.'

One area of concern which surfaced in the teachers' comments was children who exhibit 'unmanageable' behaviour. Several of the teachers felt that such children were disruptive to the class. These problems were the most common reason behind requests for technical assistance. In addition, behaviour and classroom management were the most commonly-requested training topics. These attitudes differed considerably from those towards children with physical disabilities or learning difficulties. Other than some apprehension about safety and 'knowing what to do' there was overwhelming agreement that these 'types' of children were clearly a positive addition to the classroom. Ironically, many of the children who exhibited poor behaviour were not the referred children with identified special needs; rather they were children enrolled as 'typical' children.

### Social competence

The incorporation of a social-competency-based curriculum into the pre-school programmes was a key component of this project. While all three agencies participated in training on social competence, Head Start piloted a specific curriculum for the project. The Assessment of Peer Relations (Guralnick, 1992a) was implemented with 57 young children with special needs by six teachers. This will expand to all teachers during years four and five of the project.

Some issues about the goals of pre-school and kinder-garten did emerge, particularly during discussion of the social competence curriculum with the teachers. One of the teachers, who was quite interested in the presentation, discussed her feelings about the importance of social competency for children and the challenge of explaining its importance to parents who are more interested in the development of cognitive

and motor skills. The parents, she lamented, often think the teachers are 'just playing and doing nothing and baby-sitting.' The social competency curriculum and the project in general were viewed as providing credibility for the work that the pre-school teachers do.

The challenge described above was to make parents and other outsiders understand the importance of social skills; amongst the project's participants there was little controversy. However, there was some disagreement expressed about the proper goals and methods of kindergarten teaching and how much they differ from those of pre-school. The conflict was made explicit by one of the Public School teachers in a discussion of how well the children who had experienced pre-school special education did in kindergarten and first grade. 'In my mind, kindergarten is a continuation of pre-school. It is not little academia. Unfortunately not all kindergarten teachers agree with me that teaching children how to get along with each other is more important than worksheets on ABCs.'

### Integrated health plans

This area was felt to be very important by all project participants, but a lack of team process between health and education proved a barrier to the collaborations which were necessary to get the integrated health plans completed. Head Start had a health emphasis, and felt its health care records were adequate. Unfortunately, the Head Start teachers did not have constant access to them. The Public School teachers and Day Care teachers felt that this area was problematic for them. One teacher complained that: 'I guess the law changed and the nurse in our building is not allowed to share as much as she used to share... I find it helpful when I'm allowed into the records, but they are stored at the administration building.'

#### Parent collaborations

'Parents, parents are a key.'

'A lot of support from parents and staff, 'cause I think when you have the support from both ways, you get a lot done.'

'In order to work with any of the children or all of the children, you need support from the family. You need to have the family involved, you need to know what's going on at home. Parents need to know what's going on at school.'

These comments illustrate the feelings of teachers and others related to the programme about parental involvement. They agreed that it is difficult to achieve the level of participation and support that is needed, primarily because it is difficult to get parents to come

into the schools. Several reasons were offered:

- safety in the urban neighbourhoods of the City of Hartford, many parents are afraid to travel to the school;
- distance because placement in special education is not neighbourhood based, many of the parents live some distance from their child's school;
- schedules in many families, both parents work and are unable to visit the school during the normal working day;
- stress for example, when a parent calls the school and reports that their electricity has been cut off.

In addition to these logistical problems, psychological and interpersonal barriers to family participation were identified, including the feelings of intimidation felt by some parents. One teacher said: 'and they're still very intimidated and it may be a lack of experience on their part with being in such a small room with so many kids at once. It may be that they're intimidated by "school". Maybe they didn't make it through school'. The same teacher suggested that some teachers need training ' to learn how to talk with parents without insulting them. Or making them feel like they're two inches tall. 'Cause I see that happening. And it's not done deliberately, people aren't even aware of it.'

A representative from Day Care talked about the reticence of some of the parents in talking about their children's special needs, especially when their needs are social rather than physical. 'A lot of the parents don't wanna let you in on the, those facts, either... You know the things that are physical... those are much easier to deal with because they are right there'.

A Head Start teacher raised a problem she finds with some of the families. In the classroom, she tries to get children to do as much for themselves as they can but finds that 'at home, they tend to do a lot of things for her [the child], as opposed to requiring that she do what she can for herself.' The teacher felt it would be helpful if the child's mother could observe other children at school in wheelchairs to see what they are capable of and what her child might be able to do as well.

The interviewees offered several suggestions for increasing family participation:

- increase the sensitivity of staff to parental problems and feelings
- increase the frequency of home visits
- invite parents to school functions and events
- entice parents into the school with meals
- set up parental support groups based on commonalties of child's age and/or disability.

From the perspective of teachers and staff, the key issue related to families was how to support and be supported by families at a level appropriate to the children's needs. They saw the prime problem as the families' reluctance to come to the schools and participate. Several suggestions about what is perceived primarily as a logistical problem were offered. Although helpful, these comments offer only minimal insights into the family component of the project, because the interview respondents did not include families and many of the participants did not understand how the family component related to their own concerns.

### CONCLUSION

Quality early childhood intervention requires that many agencies work together to develop joint activities focussed on the development of collaborative service models. A logical extension to this requirement for services for young children with disabilities would be the design of collaborative service models to encompass the early care and education needs of all young children. As demonstrated in this project, the challenge is to identify the various agencies, professionals and payment sources currently involved in the provision of such services. The project's goal was to develop a seamless system of service delivery which responds flexibly to a family and child's needs, as opposed to delivering an inflexible programme with artificiallyimposed limitations which reflect attitudinal, agency and funding constraints.

There are many benefits to collaborative service delivery models; most importantly, a more efficient and effective use of service providers and funding streams across agencies, resulting in improved service delivery. These models also result in a reduction in service duplication. Collaborative models enable parents and service providers efficiently to locate and manage the necessary services required by the family. Lastly, collaborative models eliminate the need for formal transitions, as services are integrated, comprehensive and longitudinal.

Unfortunately, the implementation of collaborative service models remains an elusive goal for many states and localities. There are many reasons for this, ranging from philosophical to logistical. The most challenging of these are personnel issues, primarily those involving attitude.

### **Common barriers to collaboration**

Competitiveness between agencies and providers:

- · turf issues
- lack of information about other's functions
- political issues.

Lack of organisational structure for coordination:

- differing philosophies
- independent goals
- haphazard team process
- lack of a facilitator
- lack of monitoring and evaluation process
- lack of planning
- lack of power and authority to make and implement decisions.

### Technical factors:

- resources staff, time, budget
- logistics distance, geography.

#### Personnel:

- parochial interests
- resistance to change
- staff attitudes
- · lack of commitment to community needs
- questionable administrative support
- discipline-specific jargon and perspectives.

This model demonstration project is attempting to address the development of collaborative service structures which support the needs of pre-school age children with disabilities within inclusive early childhood classrooms. The project is redefining early childhood service priorities to address all children and families within a framework of recommended best practice. Progress has been made within the project components of inter-agency collaborations, service delivery collaborations and family collaborations. Two quotes from project participants attest to the progress made in changing attitudes about the placement and inclusion of children with disabilities within early childhood. A teacher from the Day Care programme stated: 'People literally are walking in the area of the dark ages because of their lack of knowledge in the area of inclusion. Since I have been a participant of this project, I have a respect and admiration for those who seek the big picture of the diversity of being human beings.... I truly believe that it takes a special person with a heart open and receptive to the concept of inclusion and now I believe I am one of those special people. This project has opened up my understanding as well as my heart.'

A programme director also stated a belief about changes that had occurred as a result of the project. 'You [had] teachers who really were at a level that they didn't even want special needs children in their

classroom. And now you have teaching staff who actually approach us requesting that we have special needs children in their classroom, and not just children with speech delays.'

There are many more agency and family challenges to meet before all children are able to benefit from collaborative models of early childhood services. Hopefully, demonstration projects such as the Collaborative Services Model in Hartford, Connecticut, can facilitate the development and expansion of collaborations for all children.

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