The determinants of compliance with an early intervention programme for high-risk babies in India

N. de Souza,* V. Sardessai,* K. Joshi,* V. Joshi† and M. Hughes‡

*Sangath, Alto Porvorim, Goa
†Department of Pediatrics, Goa Medical College, Goa, India, and
‡Institute of Psychiatry, Kings College, London, UK

Accepted for publication 16 August 2005

Abstract

Background Early intervention is known to improve outcomes for babies at risk for growth and developmental problems. Such programmes usually have a prolonged course and require frequent contacts with the service providers. As a consequence of poverty, illiteracy and lack of communication facilities in developing countries, treatment adherence can suffer.

Methods The present study is an analysis of a clinic-based early intervention programme for high-risk babies in a developing society in Goa, India. A sample of 152 neonates and their parents were offered an early intervention programme and followed up until their first birthday. The primary outcome under study was the uptake of the programme. Various socio-demographic, programmatic and infant-related variables that could affect compliance were examined.

Results Compliance with the intervention programme was only moderate, with 59.2% of infants brought for three or more sessions. Higher maternal educational levels and proximity of the place of residence of the family to the early intervention clinic were significantly associated with better compliance.

Conclusions Early intervention programmes that go into homes have a greater chance of reaching high-risk infants, compared with those provided at a distant centre. Better-educated mothers are more likely to be convinced about the benefits of such inputs. The authors conclude with recommendations for future practice and research.

Keywords
community, compliance, early intervention, evaluation, India, predictors

Introduction

Technological advance has enabled the survival of highly vulnerable infants. However, many of these babies remain susceptible to poor growth and development in early life. With the gains made in reduction of infant mortality, the focus has shifted to improving the quality of life for these 'high-risk' babies, to ensure the best possible future for them. This is especially true in India, where the incidence of low birth weight is estimated to be around 40% (Gopalan 1994).

The benefits of early intervention were highlighted a decade ago in the seminal work of Myers (1992) that described the advantages of combined intervention programmes in nutrition and early child development. More recently, a review of various childhood care programmes implemented all over the world has reiterated the value of investing in the growth and development of children (Pelto

Correspondence
Dr Nandita de Souza, Sethu Trust for Child Development & Family Guidance, 35, Defence Colony, Alto Porvorim, Goa 403521, India
E-mail: ndesouza@sancharnet.in

et al. 1999). The United Nations Children's Fund (UNICEF), the world's celebrated organization working on behalf of children has proclaimed that the period of birth to 3 years is most favourable to intervene and promote healthy growth and development (UNICEF 2001). However, the design and components of the intervention and the mode of delivery are crucial (World Health Organization 2001). There are many models to choose from and regular and long-term adherence is required by all. In a situation where resources are meagre, clinic-based parent training is one possible approach, but whether this approach will be effective remains to be determined.

Goa, situated on the west coast of India, has an area of 3702 km^2 with a population of over 1.3 million (Government of India Census 2001). Since liberation from Portuguese rule in 1961, the state has witnessed a rapid expansion of health and other infrastructural facilities. According to the National Family Health Survey (Population Research Centre 1995) in Goa an overwhelming majority of women deliver in hospitals, especially those with high-risk pregnancies. Over 25% of newborns have a low birth weight, which can portend poor subsequent growth and development during infancy. Goa does have a good network of primary healthcare centres that cater to the remotest corners of the state (Health Intelligence Bureau 1997). Several other agencies such as the Integrated Child Development Scheme provide maternal and child health services in a systematic manner.

The effectiveness of any programme that is conducted within a community is influenced by numerous variables that are part of the realities of the world. Low participation rates are a frequent dilemma of intervention programmes, causing diminished effectiveness. This has been previously reported for parent training sessions for pre-school children with disruptive behaviour (Barkley *et al*. 2000), as well as an enriched prenatal intervention programme designed to decrease the incidence of low birth weight (Herman *et al*. 1996). Therefore, an examination of factors that constrain and promote compliance may offer opportunities to improve the effectiveness of community-based programmes. In an earlier study, De Souza and colleagues (2000) have reported on the negative impact on compliance of the distance of the early intervention centre from the place of residence. It was suggested that the difficulties of dealing with public transport and the lack of time to attend health services that are provided far away from home are likely to interfere with programme compliance.

In the present study, neonates cared for in an apex tertiary care hospital were enrolled in an early intervention programme where families brought their babies to a centre at regular intervals. The service included assessment of infant growth and development, medical care, and parental education with regard to stimulation, nutrition and child-rearing practices. The objective of this cohort study was to examine the compliance with early intervention and understand the predictors of good compliance. Our hypothesis was that intervention provided closer to the babies' homes, linked with inputs from the local grassroots health worker, would result in better follow-up rates.

Methods

Participants

During the 2-year duration of the project, from October 1999 to September 2001, 278 high-risk babies were registered in the programme, out of 609 babies discharged from the special neonatal care unit at the Goa Medical College. Three hundred and thirty-one babies were excluded from the study either because they did not fulfil the criteria for high risk or the parents refused to participate. The criteria to define 'high-risk' included low birth weight of 1800 g or below, presence of birth asphyxia (Apgar score below 5), prematurity less than 34 weeks, hyper-bilirubinemia, hypoglycaemia, neonatal meningitis, seizures and congenital anomalies. One hundred and fifty-two babies attained 1 year of age while being in the programme; these infants form the cohort of this study.

Intervention

The early intervention programme was a new service that was offered to all the high-risk babies who

were cared for in the Special Care Baby Unit of the Department of Paediatrics of Goa Medical College (GMC). All the parents who were approached to participate in the programme were given an explanation of its approach and purpose. Consent was obtained from all participating families and they were informed how to contact the investigators if needed. Infants at high-risk for developmental delay were identified in the neonatal period. They were followed up during the first year of life at a weekly outpatient clinic by a team consisting of a paediatrician, nutritionist and social worker. The growth, development and general health of these babies was monitored and parents were shown how to provide home stimulation to enhance the progress of these babies.

The families of these babies were involved in their care right from the neonatal period itself. Group discussions and talks were held covering issues such as normal child growth and development, breast feeding, infant stimulation, what parents can do and the importance of regular follow-up and monitoring of progress at the Early Intervention Clinic (EIC). Two EIC sites were established, one at GMC, and the other at a primary health centre in the district of North Goa and the same project team was available at both locations. At the first appointment after discharge, the babies were registered and an assessment of general health, growth and development was performed by the paediatrician. At every subsequent follow-up, detailed assessment of growth and development was performed. Individually tailored home intervention programmes, based on the Portage programme (Bluma *et al*. 1976) were advised to the parents at the clinic, by the social worker and nutritionist depending on the child's present developmental status and the next stage expected. Parents were also given advice and guidance on medical and behaviour problems, infant nutrition and child-rearing practices. This basic programme of early intervention, parental support and health education was implemented at the clinics within the structure of the existing health systems, and all services were provided free of charge. Follow-up timings were at the ages of 6 weeks, and 3, 6, 9 and 12 months for babies developing normally. Babies with established delay were seen more frequently.

At the North Goa primary health centre the same programme of early intervention was offered, and in addition, village-based government health workers (known as Anganwadi workers) were involved in contacting the families of high-risk babies and encouraging follow-up.

Measures

Data on neonatal health status for each child were abstracted from hospital records at the time of admission to the Special Care Baby Unit. The recruitment interview provided data on the socio-demographic status of the family: (1) parental age, (2) education, (3) employment, (4) ownership of amenities like vehicle, television and cooking gas, and (5) type of house and place of residence. Trained project staff, using standard methods measured the height, weight and head circumference of the babies. Normal growth at 1 year was indicated by weight measurement at or above the 5th centile for age using the National Centre for Health Statistics charts (Hamill *et al*. 1977). Neuro-developmental status was assessed by the paediatrician at 1 year using the Developmental Assessment Scales for Indian Infants (DASII) (Phatak 1998), a standardized test based on the Bayley Scales of Infant Development (Bayley 1969). Developmental scores are available for only 78 of the 152 infants, predominantly those who complied with the programme. However, home visits were made in a convenience sub-sample of babies who dropped out of the programme, to enable developmental status at 1 year to be included as a variable in the analysis of compliance. Normal development was indicated by a DASII score of 70 or more on the motor and mental scale. Questionnaires were devised for the purposes of this study to gather data on infant behaviour problems and maternal problems. Families who lived in North Goa had additional support provided by the Anganwadi workers, and the availability of this support has been included as a separate variable in these analyses. The main outcome measure in this study was compliance with the programme, defined as attending three or more intervention sessions in the first year.

Analysis

In the course of the study, data were collected on over 90 variables relating to parental socio-demographic situation, infant health status, and medical care. Before beginning the analysis, a subset of 13 variables that were hypothesized to have a bearing on compliance were identified, and only these variables were examined, to minimize the risk of Type I error. All the hypothesized exposure variables are shown in Table 1. The candidate exposure variables were first studied by univariate analysis with chi-squared tests, using SPSS v.10 (SPSS Inc., Chicago, IL). Mantel Haenszel crude odds ratios were obtained using Stata v.6.0 (Stata Corporation, TX, USA). All the exposure variables with significant univariate associations to the outcome, as well as any variables of special interest were studied together in a series of logistic regression models. An optimally fitting model was achieved using repeated likelihood ratio tests, yielding the adjusted odds ratios and the confidence intervals. The final model included just two exposure variables: maternal education and distance of residence from the clinic site. Logistic regression was performed using Stata v6.0.

Results

A total of 152 babies completed 1 year while registered in the early intervention programme. There were 84 boys (55.3%) and 68 girls (44.7%).

Socio-demographic features

Table 2 summarizes the main socio-demographic characteristics of the families who participated in the programme. The majority of mothers and fathers had not completed schooling, although there was a greater proportion of school completers among the fathers. The mothers ranged in age from 15 to 40 years (mean = 27.3 years) and the fathers

Table 1. Regression data for predictors of compliance

Variable	Levels	Crude odds ratio	Adjusted odds ratio	95% confidence intervals
Mother's education	Some college education	2.33	3.36*	1.08–10.48
	School completers	1.20	1.3	0.53–3.14
	School non-completers	1	1	1
Father's education	Some college education	1.96	1.71	0.56–5.28
	School completers	0.99	1.00	0.44–2.27
	School non-completers	1	1	1
Father's occupation	Professional	0.93	0.57	0.21–1.53
	Skilled	0.80	0.60	0.26–1.38
	Unskilled	1	1	1
Television	Ownership of TV	1.37	1.41	0.52–3.86
Residence	Within 30 km of centre	2.39	2.96**	1.47–5.95
Gender	Female	1.51	1.72	0.85–3.49
High-risk factors	Over four high-risk factors	5.15	4.26	0.49–36.93
Behaviour problems	Presence of behaviour problems at 1 year	1.04	1.06	0.10–11.0
Abnormal development	Presence of delay at 12 months	0.80	0.67	0.06–7.37
Stay in neonatal unit	Over 1 month	1.49	1.52	0.30–7.61
	11–30 days	0.98	1.03	0.46–2.29
	Less than 10 days	1	1	1
Age of entry into programme	After 1 month post-natal	0.73	1.02	0.36–2.85
	2–4 weeks	1.03	1.36	0.55–3.39
	Below 2 weeks	1	1	1
Anganwadi intervention	Presence of input	1.72	1.10	0.36–3.40
Maternal problems	Poor health in mother	1.44	1.41	0.13–15.33

*$P = 0.037$; **$P = 0.002$.

Logistic regression data examining determinants of compliance for 152 infants who completed 1 year of follow-up in the early intervention programme.

Compliance was defined as attending 3+ follow-up sessions. Adjusted ORs are adjusted for maternal education and residence. Data on developmental delay available on only 78 infants.

95% confidence intervals are presented for adjusted odds ratios only.

were 20–48 years old (mean = 32.5 years). Over 90% of mothers were homemakers. Most of the fathers were either skilled (37.5%) or unskilled (also 37.5%) workers. The rate of unemployment was low at 2.0%. Over 50% of families owned a television and a fifth possessed a fridge or a scooter.

Table 2. Socio-demographic information

Characteristic	Number	%
Mother's education*		
School non-completers	103	67.8
School completers	28	18.4
College education	20	13.2
Father's education		
School non-completers	81	53.3
School completers	46	30.3
College education	25	16.4
Religion		
Hindu	124	81.6
Christian	16	10.5
Muslim	12	7.9
House type		
Mud hut	21	13.8
Concrete structure	131	86.2
Presence of amenities		
Electricity	144	94.7
Tap water	73	48
Car	2	1.3
Television	83	54.6
Fridge	34	22.4
Telephone	13	8.6
Type of family		
Joint	52	34.2
Extended	38	25
Nuclear	62	40.8

*Information on education was missing for one mother.
Data presented for 152 families.

Hinduism was the religion of the majority (81.6%) whereas there were lesser proportions of Christians (10.5%) and Muslims (7.9%). Nuclear families with 2 children (range = 1–7; median = 2) was the most usual pattern.

Infant characteristics

Important infant attributes are depicted in Table 3. All the babies were born in hospital. The most common criterion of high risk was intrauterine growth retardation, seen in 58.6% of babies. Other factors included prematurity (29.6%), presence of neonatal jaundice beyond physiological limits (33.6%), lack of oxygen at birth (26.3%) and low blood glucose levels (21.1%). Babies had between one to five high-risk factors. The average number of high-risk factors was 2.0 (SD = 0.91). At the age of 1 year, only 28 out of 78 babies (35.9%) had achieved normal weight. Developmental status at this time was abnormal in 17 of 78 babies (21.8%).

Hospitalization

The average length of hospital stay in the special care baby unit for these high-risk babies was 16.3 days. After discharge, the families were asked to bring their babies for follow-up to the early intervention clinic within 2 weeks. However, this advice was not always followed and the average age of first follow-up was 4.4 weeks.

Table 3. Infant characteristics of 152 high-risk babies

Infant attribute	Value
Gestational age at birth	Median 40 weeks, range = 29–42 weeks
Birth weight	Median 1.85 kg, range = 0.80–3.70 kg
Total high-risk factors	Mean = 2.0; range = 1–5; SD = 0.91
Presence of intrauterine growth retardation	*n* = 89 (58.6%)
Presence of prematurity	*n* = 45 (29.6%)
Presence of birth asphyxia	*n* = 40 (26.3%)
Presence of hyper-bilirubinemia	*n* = 51 (33.6%)
Presence of neonatal meningitis	*n* = 17 (11.2%)
Presence of neonatal seizures	*n* = 12 (7.9%)
Age at discharge from hospital	Median 15 days, range = 3–60 days
Age of entry into intervention programme	Median = 3 weeks, range = 1–22 weeks
Number of babies who were breastfed during infancy*	*n* = 53 (67.7%)
Presence of abnormal growth (weight below 5th centile) at 1 year*	*n* = 50 (64.1%)
Presence of abnormal development (DASII score below 70) at 1 year*	*n* = 17 (21.8%)

*Information available for 78 babies only.

Table 4. Compliance with the programme

Number of sessions attended	Number of babies	Percentage
Non-compliant (40.8%)		
1	37	24.3
2	25	16.5
Compliant (59.2%)		
3	16	10.5
4	17	11.2
5	21	13.8
6	32	21.1
7	3	2.0
8	1	0.7
Total	152	100

Compliance

The details of compliance are shown in Table 4. Out of the 152 babies in the cohort, 90 (59.2%) were compliant. The remainder ($n = 62$) babies dropped out of the programme after attending only one or two clinic sessions.

An analysis was done of the various exposure variables that could have been linked to the outcome of compliance at 1 year. The socio-demographic variables studied included parental education and occupation, socio-economic indicators, such as presence of household amenities (cooking gas, television) and place of residence. Factors related to the infant included gender of the child, total number of high-risk factors present at birth, the duration of stay in hospital during the neonatal period and the presence of development or behaviour problems. Programmatic variables included age of entry into the programme and whether that infant received inputs from the local grassroots health worker. The effect of the presence of health problems in the mother was also studied. Logistic regression modelling was used to identify significant determinants of compliance, and to adjust each of these for confounding. The crude and adjusted odds ratios for the various exposure variables associated with compliance are presented in Table 1.

Mothers who had a college education were over three times more likely to comply with the programme ($P = 0.037$). This effect remained even after adjusting for other factors. Although compliance improved with higher levels of education in the father, this was not statistically significant. There was no effect of the father's occupation, religion or socio-economic status as judged by ownership of cooking gas or TV. There was a significant effect of distance of residence from the centre. Babies living within 30 km of the centre were almost three times more likely to comply compared with those living beyond this distance ($P = 0.002$).

Female babies were almost twice as likely to comply compared with male infants, but this was not statistically significant. There was a trend for babies with multiple perinatal high-risk factors to be fully compliant, whereas those with an established developmental delay at 12 months were less likely to have been compliant, although neither of these trends achieved statistical significance. Other factors such as the duration of stay in hospital during the neonatal period and the presence of behaviour problems did not have any bearing on compliance. Similarly, the age of entry into the programme, the addition of Anganwadi worker input and the health of the mother did not affect compliance.

Discussion

In the present study, the outcome of interest was the uptake of the programme and the links between this and several potential determinants of compliance. Overall, compliance with this free, professionally staffed clinic service was only moderate. If a clinical service achieves only 60% compliance, it is difficult to imagine how the service can be fully effective in achieving its objectives. Possible causes and implications of poor compliance are discussed below.

One objective of the study was to examine the effect of adding Anganwadi worker training and support for the clinics. Our results indicate that Anganwadi worker involvement does not improve compliance when her role is simply to motivate families to attend an early intervention service provided elsewhere. If such grassroots health workers are to play a role in secondary and tertiary prevention of disability, alternative models of working will therefore need to be examined.

The second study hypothesis was that geographical accessibility, as indicated by closeness of resi-

dence to the EI clinic, would predict improved compliance. This hypothesis was confirmed. It appears that parents are not willing to travel long distances to a centre that provides only preventative and rehabilitation services. A likely factor in the poor follow-up at a distant centre is the fact that a woman's work is never done. Most babies are brought to the clinic by their mothers. With the demands of housework, the long delays associated with travelling by public transport and a possible lack of support from spouses and mothers-in-law, the mothers are likely to find it very difficult to adhere to their clinic appointment schedules. In some cultures too, taking very young babies out of the home is considered inappropriate, exposing the vulnerable infant to infection and the evil eye. Therefore, rather than expect mothers and babies to come to the programme, the programme must go to the homes.

Several other factors were examined as covariates and potential confounders. These included socio-demographic factors (such as socio-economic status of the family, parental education and occupation), child-related variables (such as gender, number of high-risk factors, growth and development problems), and programmatic variables (such as age of starting an early intervention programme). In *post hoc* analyses, only one further factor, maternal education, was found to be a significant independent predictor of compliance. It is probable that mothers who are better educated are more likely to be aware of the benefits of early intervention and are thus inclined to avail of the programme services. Almost universally, mothers are the primary caregivers of children and have a direct influence on their well being and use of health services. There are several studies that demonstrate strong links between maternal education and compliance with a range of medical services. These include treatment of tuberculosis in children (Oviawe & Ojemudia 1993), DPT immunization (Zeitlyn *et al.* 1992) and adherence to nutritional recommendations for milk allergy (Schoetzau *et al.* 2002). It is well established that maternal literacy is inversely related to infant mortality (Indian Council of Medical Research 1990). The benefits of female education are likely to translate into better health practices during motherhood. Infant gender has been an important variable in the utilization of health services. Male babies with disabilities are more likely to be brought for therapy (McConachie *et al.* 2001). However, in this study the trend was for female babies to have a better compliance rate.

Our data indicate that medical need, as defined by either multiple perinatal risk factors for disability, or by established intellectual delay, did not lead parents to bring their infants for an early intervention programme. Although there was a trend for infants with multiple perinatal risk factors to be more compliant, neither measure of need was significantly associated with compliance with the programme. This may indicate that the parents' perceptions of need were different from those of the professionals, although this aspect was not measured in the present study. In a study of the factors influencing participation of children in an early intervention programme, Kuchler-O'Shea and colleagues (1999) reported that caregivers identified an improvement in the child's skills as the most important reason for attendance. Smith and colleagues (2000) have reported that attendance at training sessions for children with developmental delay was better when the mothers believed that professional intervention, rather than chance, was responsible for improvement in the child's status. Since in this study there were babies with developmental delay who did not come for follow-up, it is possible that the persistence of skill deficits in these babies led to a lack of conviction in the benefits of early intervention among the concerned families and subsequent drop-out.

Limitations

There were several limitations of this study. With only a small sub-sample of babies accessing services in the EIC in North Goa, the power of the study to detect an effect of grassroots health worker inputs may have been inadequate. Resource constraints dictated that follow-up was not feasible in those babies who defaulted in the programme. Limited project funding precluded the extension of the time frame to enable the inclusion of more babies. Lack of personnel and transport also interfered with our ability to perform home visits in those babies who

did not comply with the programme. The disability team did not include any therapists due to non-availability of trained staff. Additionally, the study did not include an assessment of parental adaptation, stress, needs or expectations from the programme, factors that are known to determine the extent of health usage (Jensen *et al*. 1990). Therefore no comment can be made on important variables related to parental stress or other family circumstances that affect compliance. In children with cerebral palsy, it has been reported that mothers with lower adaptation were more likely to bring their children for follow-up (McConachie *et al*. 2001). Yet another serious limitation was lack of information about parental satisfaction through direct feedback. This too could have afforded important insights into why families failed to comply with this particular service.

Raising a child with special needs is a challenging task for families (Ray 2002), resulting in major alterations to how they live, work and care for the children. Quality of life measures have been extensively used in the assessment of the impact of childhood disability on families (Eker & Tuzun 2004; Wake *et al*. 2004; Tamarit 2005). Although it is very possible that this aspect would also influence compliance with early intervention programs, unfortunately no information is available here, as quality of life measures were not incorporated in the present study.

We were unable to gather data about mortality in study participants as home visits were not routinely done. It is possible that since we were caring for a high-risk infant population, this factor may also have contributed to the low follow-up rates.

Improving compliance

When compliance is vital in effecting change in health status, finding strategies to improve it poses a tough challenge to service providers. There have been several endeavours reported in the literature, some rather unusual. In the field of developmental disabilities, Terry (1981) has highlighted the role of a key social worker, who works closely with the multidisciplinary team and provides assistance in diverse ways from marriage counselling to crisis intervention. Others (Kolomer *et al*. 2003) have demonstrated the positive effect of caregiver support groups and benefits such as transportation, respite and flexibility of treatment session schedules. Elder and Salgado (1988) have reported partial 25% improvement in attendance rates at well baby clinics in Mexico using a lottery system. The provision of gifts increased participation in a community-based growth monitoring programme by 25 to 77.3% in Indonesia (Johnston 1991). However administrative problems hampered the implementation of both the latter incentive programmes. This highlights the fact that families need more than mere sops to be convinced that compliance with health programmes will result in long-term benefit to their children.

The paramount question that must be addressed is what kind of intervention is most likely to result in good uptake, keeping in mind the issues of cost, effectiveness and sustainability. Greater coherence between health programs and the needs of the local community and culture are crucial in ensuring sustainability of services (Ager 1990). We have shown that services provided close to the family home, are more likely to result in good compliance. However, there is a substantial problem in attempting to locate services closer to the family home in a low-income setting. The availability of trained professionals diminishes sharply outside large, urban centres (World Health Organization 2001). Therefore, the ideal of a professional, multidisciplinary team providing an intervention close to home cannot at present be a workable model of EI in most low-income countries. The only available resources at a local level are families and primary healthcare workers. Extended families are commonplace in India and there are often other family members besides the parents who are involved in the care and development of young children, and the involvement of families in EI intervention has been highlighted previously (Sturmey *et al*. 1992).

It is plausible that training the Anganwadi worker to deliver the EI programme herself may be more effective than simply using the AW as a support-worker for a clinic-based service, although this study did not allow us to examine this hypothesis. If good compliance is a necessary precursor for children to benefit from EI activities, then delivering the programme through community-based

health workers would have obvious advantages. Home visiting has been shown to be an effective element of programmes targeting low birth weight, premature infants (Olds & Kitzman 1993). Anganwadi workers are already in close contact with families, providing advice on breast-feeding, nutrition, immunization and child care for parents of older pre-school children. Their role could be extended to include instructing parents to use simple stimulation activities with their babies, in order to improve their development. Strengthening the primary care worker's resource base of skills will ensure the optimal use of manpower available at the grassroots. This seems an attractive option in a situation where highly trained professionals are largely unavailable and high-risk babies from socio-economically disadvantaged families live over a wide geographical area, with poor access to centre-based services. However, further research would be required to investigate this hypothesis.

Undoubtedly there is a need for well-controlled community-based trials to replicate the effectiveness studies from western countries. Our data give some indication of the format of early intervention services that is most likely to be effective in a low-income country like India. It appears that parents of high-risk babies may not universally take up even a free service, administered by highly trained professionals. Babies born to less educated mothers may be particularly poorly compliant. Programmes that are provided close to the homes of the families have a greater chance of reaching high-risk infants, compared with those provided at a distant centre.

Acknowledgements

The authors would like to thank Child Relief and You, Mumbai for providing the funding for the study and the Department of Pediatrics, Goa Medical College, the Directorate of Health Services, Goa and the Integrated Child Development Scheme, Goa for logistical support.

References

Ager, A. (1990) The importance of sustainability in the design of culturally appropriate programmes of early intervention. *International Disability Studies*, **12**, 89–92.

Barkley, R. A., Shelton, T. L., Crosswait, C., Moorehouse, M., Fletcher, K., Barrett, S., Jenkins, L. & Metevia, L. (2000) Multi-method psycho-educational intervention for preschool children with disruptive behavior: preliminary results at post-treatment. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **41**, 319–32.

Bayley, N. (1969) *Bayley Scales of Infant Development*. Psychological Corporation, New York, NY, USA.

Bluma, B. S., Shearer, M., Frohman, D. & Hillard, J. (1976) *Portage guide to early education.* Co-Operative Educational Service Agency, Portage, WI, USA.

De Souza, N., Patel, V., D'Souza, P. & Rao, H. B. (2000) Determinants of follow-up in an early intervention programme in high-risk babies. *Indian Paediatrics*, **37**, 986–989.

Eker, L. & Tuzun, E. H. (2004) An evaluation of quality of life of mothers of children with cerebral palsy. *Disability Rehabilitation*, **26**, 1354–9.

Elder, J. P. & Salgado, R. (1988) The well baby lottery: motivational procedures for increasing attendance at maternal and child health clinics. *International Journal of Health Services*, **18**, 165–71.

Gopalan, C. (1994) *Nutrition Research in South East Asia – the Emerging Agenda of the Future*. Regional Office for South East Asia, World Health Organisation, New Delhi, India.

Government of India Census (2001) *Provisional Population Data, Paper I & Paper II.* Census of India, Panaji, Goa State, India.

Hamill, P. V. V., Drizd, T. A., Johnson, C. L., Reed, R. B. & Roche, A. F. (1977). *National Centre for Health Statistics Growth Curves for Children: Birth to 18 years.* United States, NCHS/Series II, No. 165, DHEW/PUB/PH5, Hyattsville, 78-1650.

Health Intelligence Bureau (1997) *Directorate of Health Services.* Health Profile Goa, Panaji, Goa, India.

Herman, A. A., Berendes, H. W., Yu K. F., Cooper, L. C., Overpeck, M. D., Rhoads, G., Maxwell, J. P., Kinney, B. A., Koslowe, P. A. & Coates, D. L. (1996) Evaluation of the effectiveness of a community-based enriched model prenatal intervention project in the District of Columbia. *Health Services Research*, **31**, 609–21.

Indian Council of Medical Research (1990) *A National Collaborative Study of Identification of High Risk Families, Mothers and Outcome of Their Offspring with Particular Reference to the Problem of Maternal Nutrition, Low Birth Weight, Perinatal and Infant Morbidity and Mortality in Rural and Urban Slum Communities (An*

ICMR Task Force Study). Indian Council of Medical Research, New Delhi, India.

Jensen, P. S., Bloedau, L. & Davis, H. (1990) Children at risk: 11: Risk factors and clinic utilisation. *Journal of the American Academy of Child and Adolescent Psychiatry*, **29**, 804–812.

Johnston, M. (1991) Incentive for growth monitoring: why and how. *Vibro*, **69**, 24–5.

Kolomer, S. R., McCallion, P. & Overeynder, J. (2003) Why support groups help: Successful interventions for grandparent caregivers of children with developmental disabilities. In: *Working with Custodial Grandparents* (eds B. Hayslip & J. H. Patrick), pp. 111–125. Springer Publishing Co., New York, NY, USA.

Kuchler-O'Shea, R., Kritikos, E. P. & Kahn, J. V. (1999) Factors influencing attendance of children in an early intervention program. *Transdisciplinary Journal*, **9**, 61–68.

McConachie, H., Huq, S., Munir, S., Kamrunnahar, Akhter, N., Ferdous, S. & Khan, N. Z. (2001) Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh. *Child: Care, Health and Development*, **27**, 1–12.

Myers, R. (1992) *The Twelve Who Survive: Strengthening Programmes of Early Childhood Development in the Third World*. Routledge, London, UK.

Olds, D. L. & Kitzman, H. (1993) Review of research on home visiting for pregnant women and parents of young children. *Future of Children*, **3**, 53–92.

Oviawe, O. & Ojemudia, E. (1993) The problem of non-attendance at a paediatric tuberculosis outpatient clinic. *Annals of Tropical Paediatrics*, **13**, 243–7.

Pelto, G., Dickin, K. & Engle, P. (1999) A critical link. In: *Interventions for Physical Growth and Psychological Development – A Review*. (ed. M. Mikulencak), pp. 1–79. WHO, Geneva, Switzerland.

Phatak, P. (1998) *Developmental Assessment Scales for Indian Infants*. Anand Agencies, Pune, Maharashtra, India.

Population Research Centre, J.S.S. Institute of Economic Research, (PRC, Dharwad) and International Institute for Population Studies (IIPS) (1995) *National Family Health Survey (MCH and Family planning), Goa 1992–93*. PRC, Dharwad and IIPS, Bombay, India.

Ray, L. D. (2002) Parenting and Childhood Chronicity: making visible the invisible work. *Journal of Pediatric Nursing*, **17**, 424–38.

Schoetzau, A., Gehring, U., Franke, K., Grubl, A., Koletzko, S., von Berg, A., Berdel, D., Reinhardt, D., Bauer, C. P. & Wichmann, H. E. (2002) Maternal compliance with nutritional recommendations in an allergy preventive programme. *Archives of Disease in Childhood*, **86**, 180–4.

Smith, T. B., Oliver, M. N., Boyce, G. C. & Innocenti, M. S. (2000) Effects of mothers' locus of control for child improvement in a developmentally delayed sample. *Journal of Genetic Psychology*, **161**, 307–313.

Sturmey, P., Thorburn, M. J., Brown, J. M., Reed, J., Kaur, J. & King, G. (1992) Portage guide to early intervention: cross-cultural aspects and intra-cultural variability. *Child: Care, Health and Development*, **18**, 377–94.

Tamarit, J. (2005) Autism: educational models for a quality life. *Revista de Neurologia*, **15** (**40** Suppl. 1), S181–6. [Article in Spanish].

Terry, P. O. (1981) Clinical social work roles in an integrative, interdisciplinary team; enhancing parental compliance. *Social Work in Health Care*, **6**, 1–15.

UNICEF. (2001) *The State of the World's Children 2001*. UNICEF, New York and Oxford University Press, Oxford, UK.

Wake, M., Hughes, E. K., Collins, C. M. & Poulakis, Z. (2004) Parent-reported health-related quality of life in children with congenital hearing loss: a population study. *Ambulatory Pediatrics*, **4**, 411–17.

World Health Organization (2001) *The World Health Report: 2001: Mental Health: New Understanding, New Hope*. WHO, Geneva, Switzerland.

Zeitlyn, S., Rahman, A. K., Nielsen, B. H., Gomes, M., Kofoed, P. E. & Mahalanabis, D. (1992) Compliance with diphtheria, tetanus, and pertussis immunisation in Bangladesh: factors identifying high risk groups. *British Medical Journal*, **304**, 606–9.