

# A randomized controlled trial of alternative modes of service provision to young children with cerebral palsy in Bangladesh

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**Objective:** To compare the efficacy of an outreach program for young children with cerebral palsy with center-based and “minimal intervention” control groups.

**Design:** Randomized controlled trial conducted in a group of 85 children between the ages of 1.5 and 5 years. Urban children were allocated to a daily center-based mother-child group or to monthly training of their parents along with a pictorial guidance manual. Rural children were allocated either to parent training or health advice. Outcome measures were changes in children’s adaptive skills, maternal stress and adaptation to the child, satisfaction with social support, and knowledge of handling a physically disabled child.

**Results:** Fifty-eight children were successfully followed up. The pattern of change in children’s adaptive skills was as predicted (ie, least progress in the health advice group). Positive effects of intervention also included increased maternal knowledge and perceived helpfulness of support from formal sources. However, maternal adaptation increased most in the health advice group with minimal intervention. When children had attended a program at least 4 times, their skills improved, and mothers’ adaptation did increase.

**Conclusions:** Outreach training for mothers in Bangladesh can help them to improve the skills of their young children with cerebral palsy and is perceived as helpful. (J Pediatr 2000;137:769-76)

## IBAS Independent Behaviour Assessment Scale

The majority of disabled children live in developing countries. A large epidemiologic study of disability in children aged 2 to 9 years indicated a prevalence rate in Bangladesh of 6.8% for all levels and types of disabilities (motor, vision, hearing, cognition, epilepsy) and 1.5% for serious disabilities.<sup>1,2</sup> Given a population of 120.4 million (almost half <18 years of age),<sup>3</sup> approximately half a million children under 10 years of age will have a serious disability. Eighty-one percent of the population lives in rural areas, with poor infrastructure of roads, bridges, and rail links. There are very few services for disabled people and their families, particularly for children of preschool age. There is thus a need for innovative service delivery and for evaluation of the effectiveness of different models.

## See editorial, p 746.

Such services as there are in developing countries have frequently been institution-based, reaching only a small proportion of disabled children.<sup>4</sup> Models of early intervention services have included community-based groups in which children and parents meet together for learning and enjoyment,<sup>5</sup> training manuals to spread rehabilitation knowledge,<sup>6</sup> and home-based teaching programs often staffed by trained volunteers.<sup>7</sup> The evaluation described in this study contrasts the outcomes of 3 types of intervention: health

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**Table I.** Summary of treatment conditions

Distance training packages	Mother-child group	Health advice
Monthly Individual with therapist Demonstration and practice of techniques Pictorial manual to take home	Available daily With other mothers and therapist Demonstration and repeated practice of techniques	One contact Individual with pediatrician Health advice, nutritional supplements Box of toys and books to take home

and nutrition advice, a parent training program with a pictorial manual of techniques demonstrated and then given to parents, and a regular group session with a rehabilitation worker involving children and their mothers.

Evaluation of outcome is complex, because any program will have a range of objectives. There are limitations on what is known from evaluation research on early intervention for young disabled children even in Western countries.<sup>8</sup> Many questions remain, including the identification of the interventions that work best for particular populations. For example, a program that appears to have a beneficial effect on child skill levels may exacerbate stress in deprived parents, with concomitant lack of progress in their children.<sup>9</sup> A well-designed evaluation in Tower Hamlets, London (with a large population of families originally from Bangladesh), showed that supporting mothers in meeting their priority needs was as important as child-focused rehabilitation in a range of outcome measures.<sup>10</sup>

Our first hypothesis was that an outreach parent training program would be effective in promoting the adaptive skills of young children with cerebral palsy and in improving the situation for their mothers and would be as effective as an urban center-based group program. The second hypothesis was that, in a rural area, the outreach parent training program would show greater benefits for children and their mothers than a "minimal intervention" of health care advice. The study was conducted from clinics at 2 school

bases of the Bangladesh Protibondhi Foundation, a local non-governmental organization that has been offering a range of services to children with intellectual and physical impairments since 1986. One special school is in central Dhaka; the other community school is near Dhamrai in a rural setting 50 km north of Dhaka. Both urban and rural locations were included in order to examine the effectiveness of the parent training model of intervention under varied conditions.

## METHODS

### *Participants*

Between May 1993 and July 1995, 92 children met the inclusion criteria. Children between the ages of 1.5 and 5 years at presentation were recruited if they lived in Dhaka or within 15 km of the rural base. The children were assessed by a neurodevelopmental pediatrician to have cerebral palsy. Recruitment continued for 2 years. In the rural area, it was thought by experienced community workers to include all eligible children.

### *Design and Procedures*

The study was a randomized controlled trial with 2 arms for the urban children (a center-based mother-child group vs outreach parent training) and 2 arms for the rural children (outreach parent training vs health advice only) (see Table I and descriptions below). The study protocol was approved by the Ministry of Social Welfare, Bangladesh.

After the initial assessment and random assignment, the pediatrician ad-

vised the parents to enroll in the allocated intervention program or provided health advice and a box of toys for the child. The pediatrician also invited the family to return for primary health care if the need arose. In gaining verbal voluntary consent for the assessment procedures, parents were told that the methods of helping their children were being evaluated and that the professional team wanted "to see how the child is doing after 9 months." Written consent was not sought because female literacy in Bangladesh is only 26%.<sup>3</sup> The final assessment was intended to be undertaken 9 to 12 months after the initial assessment. At that point, all parents in the health advice group were offered further intervention to suit the family needs.

### *Interventions*

**DISTANCE TRAINING PACKAGES.** The study included 2 parent training programs, one urban and one rural. The Bangladesh Protibondhi Foundation staff developed distance training packages as a simple outreach way of giving advice to parents of disabled children who lived far from the Foundation schools. The pictorial manuals illustrate positions, activities, and simple home-made aids adapted for children with impairments, based on well-established sources,<sup>11-14</sup> and different manuals cover motor skills, speech and language, and cognitive skills. The suggestions appropriate to the child's stage of development are practiced with parents in a 1- to 2-hour session before they take the manual home. The "therapists" are special edu-

**Table II.** Demographic and intervention characteristics

	Urban		Rural	
	Distance training (n = 16)	Mother-child group (n = 11)	Distance training (n = 19)	Health advice (n = 12)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<b>Child variables</b>				
Age at first assessment* (mo)	36.1 (9.3)	32.6 (12.5)	44.8 (13.3)	39.0 (15.0)
	n (%)	n (%)	n (%)	n (%)
Boys	13 (81)	6 (55)	15 (79)	7 (58)
Severe motor disability malnourishment*	7 (44)	7 (64)	5 (26)	7 (58)
Mild/none	4 (25)	5 (45)	2 (11)	1 (8)
Moderate	8 (50)	4 (36)	4 (21)	6 (12)
Severe	4 (25)	2 (18)	13 (68)	5 (42)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<b>Family variables</b>				
Father's age (y)	37.9 (8.4)	33.9 (8.5)	33.0 (5.3)	34.6 (7.8)
Mother's age (y)	28.0 (5.3)	24.6 (6.7)	24.1 (3.8)	25.3 (5.0)
No. of siblings	1.8 (1.7)	1.5 (1.5)	0.9 (1.1)	2.2 (2.0)
Family income* (Taka† per mo)	4900 (3205)	5345 (3200)	2095 (1229)	4383 (5213)
	n (%)	n (%)	n (%)	n (%)
No land	6 (40)	7 (70)	12 (63)	2 (18)
No education				
Father	2 (13)	1 (9)	6 (31)	4 (33)
Mother*	3 (20)	2 (18)	10 (56)	5 (42)
Joint family	8 (53)	2 (18)	7 (37)	4 (33)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<b>Intervention</b>				
No. of attendances	6.0 (2.9)	24.4 (22.7)	6.5 (3.1)	—
Interval to second assessment (mo)	19.9 (9.2)	24.2 (10.3)	16.9 (10.2)	13.6 (6.6)

\*Significant difference between urban and rural samples ( $P < .02$ ).

†Forty-eight Taka = US \$1.

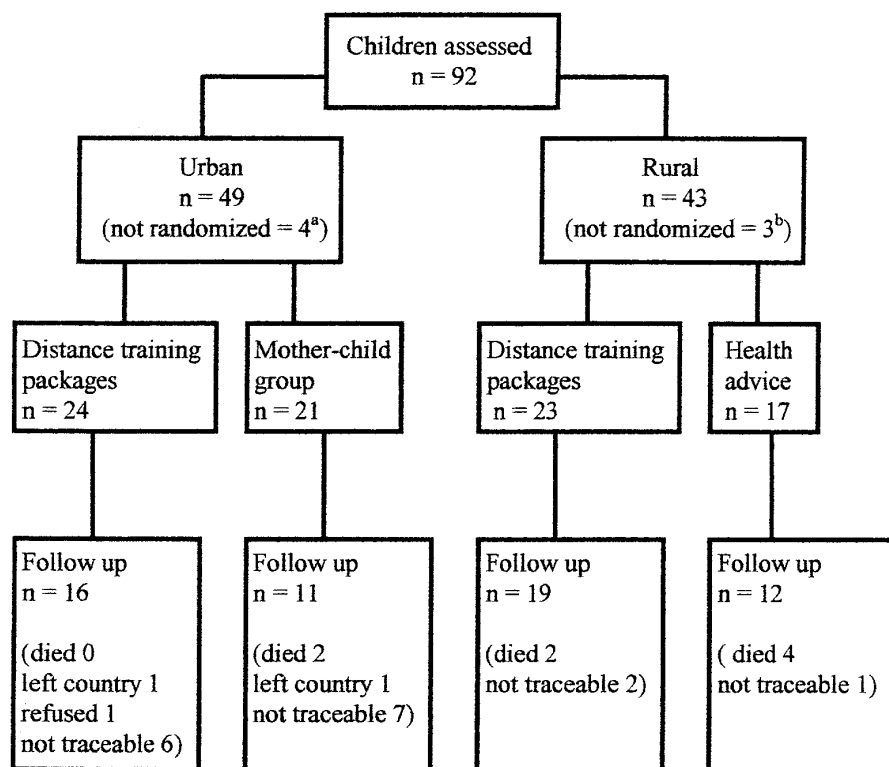
cation teachers with additional in-service training in physiotherapy or speech therapy. Preliminary studies involving matched small groups of children suggested equal progress in motor skills compared with attendance in a classroom group.<sup>15</sup> For the evaluation study, parents were asked to return to the clinic at monthly intervals.

**MOTHER-CHILD GROUP.** The mother-child group intervention was held in a part of the Bangladesh Protibondhi Foundation urban special school. The

mother-child stimulation group was offered daily, led by a therapist with extra training in physiotherapy, and involved both the children and their parents. It was thus a center-based, regular attendance intervention. Practice in daily living skills such as using a cup and developmental activities such as sorting by color were included.

**HEALTH ADVICE GROUP.** The parents and children in the health advice group were usually seen only at the beginning of the study and then not again until

invited to attend the final assessment. The child's health was discussed as part of the assessment, and then nutritional advice and vitamin supplements were given to the parents as appropriate (this also applied to the other intervention groups on the first assessment). The parents in the health advice group were not given detailed advice on positioning or other techniques but were given a box of simple local toys and books for their children to play with at home (not given to parents in the other groups). This "minimal inter-



a recently entered mother-child group  
b allocated to health advice; lived too far away to return potentially monthly

Fig 1. Randomization of potential sample of children with cerebral palsy.

vention” thus offered something more to children than would have been available at their local health clinic.

**Measures**

**SOCIO-DEMOGRAPHIC CHARACTERISTICS.** Parents’ age and education, number of siblings, composition of the household, land ownership, and other demographic factors, were recorded by using the Household Form, which was developed for the Rapid Epidemiological Assessment of Childhood Disabilities study in Bangladesh (REA).<sup>16</sup>

**CHILD CHARACTERISTICS.** Comprehensive neurodevelopmental assessment was done by a pediatrician (S.F.) for all 92 children with the Medical Assessment Form used in the REA study.<sup>16,17</sup> The degree of child disabilities was rated by using a modified ver-

sion of the World Health Organization criteria (International Classification of Impairments, Disabilities and Handicaps).<sup>18</sup> Cerebral palsy was classified into the following types: diplegia, tetraplegia, hemiplegia, dyskinetic, and mixed.<sup>19</sup> Other pediatric diagnoses were also established, and the degree of malnutrition was determined by calculating weight-for-age z scores for the children (compared with the US National Health Center for Health Statistics growth charts).<sup>20</sup>

The Independent Behaviour Assessment Scale, developed and standardized in Bangladesh,<sup>21</sup> was used for the measurement of adaptive skills in 4 areas: communication, socialization, motor skills, and daily living skills. Items are completed through direct testing, with a few completed by interview with a caregiver. Total scores are

presented as z scores, because the standardization sample scale scores were normally distributed at each age level.

**MATERNAL MEASURES.** Self-Report Questionnaire<sup>22</sup> measures maternal stress with 20 items answered yes or no. Maternal Adaptation to the Child (Judson Scale)<sup>23</sup> is measured by 22 semantic differential items on a 7-point scale. Family Support Scale<sup>24</sup> measures perceived helpfulness of 18 sources of support from family and community, distinguishing between informal (eg, parents, work colleagues) and formal (eg, doctor, teacher, day care center) sources. Each applicable item is rated on a 5-point scale. Parental Knowledge is a 10-item questionnaire developed for the study; each item has multiple possible answers scored 0, .5, or 1, to assess the mother’s knowledge of the type of information contained in the distance training package manuals (eg, “When a child with a physical problem starts to eat solid food, we should hold him/her: lying on our arm [score 0]; sitting up supported [score 1]”).

The child adaptive behavior skills assessment and questionnaire measures with mothers were carried out by a psychologist (S.M.) who was not part of the usual clinic team and who was blinded to group allocation. The measures were chosen as culturally appropriate for use in Bangladesh to show change in children’s skills independent of the direct content of the training given to mothers and to show change in mothers’ attitudes and situation, as well as knowledge (ie, broader potential effects of intervention).

**Statistical Analysis**

One-way analysis of variance, t tests, and  $\chi^2$  tests were used to examine equivalence of groups at initial assessment. The evaluation of change to detect impact of intervention was estimated within each group separately by using t tests. The hypothesis concerning difference in mean amount of

change between the 2 rural groups and the null hypothesis for the 2 urban groups were also tested by using *t* tests. Associations with child progress were examined with Pearson correlation and the Mann-Whitney *U* test. The level of significance was set conservatively at  $P < .02$  (2-tailed) because of the number of individual calculations.

Children's adaptive skills as measured by the IBAS are presented as *z* scores, which in children with impairments may be expected generally to lie below the population mean (ie, negative values). Over time, their *z* scores can be expected to fall further,<sup>25</sup> even though the child is developing some new skills, because the *z* score compares the rate of development with the norm. Thus a positive effect of intervention will be shown by the *z* score remaining relatively constant, implying an increased rate of acquisition of new skills in comparison with preceding months and years.

## RESULTS

Of the 92 children, 7 were not randomly allocated to an intervention group, and their data were dropped from analysis (Fig 1). Of the 85 children randomized, 58 were available for the follow-up assessments. Eight children had died within 10 months of the first assessment; all were malnourished and among the more severely disabled of the study children.<sup>26</sup> In the urban area, the research team sent repeated letters and made some home visits aiming to encourage parents to return for the follow-up assessment, including offering to pay for transportation costs, but 13 were not traceable. Many urban families retain strong ties with their village of origin and return if, for example, a family member is ill. In the rural area, follow-up was more complete because there is less mobility of families, and the school has an attached community worker who could transport families for assessment. In all, there was

77% follow-up in surviving children, which may be regarded as reasonable given the difficulties of the setting.

There were no group differences between those children included in the final analyses and those lost to follow-up (leaving aside those who had died). There were no differences in dependent measures in the initial assessment.

### *Description of the Groups Before Intervention*

Of the 58 children followed up, 71% were boys (Table II). Twenty-six children had severe motor disability and 32 had mild or moderate motor disability; 28 had diplegia, 21 tetraplegia, and 7 hemiplegia; one had dyskinesia and one had a mixed type of cerebral palsy. There were significant differences between urban and rural samples in child age at first assessment ( $t = 2.39$ ,  $P = .02$ ) and in the proportion severely malnourished (urban, 23%; rural, 56%;  $\chi^2 = 6.51$ ,  $P = .01$ ).

In terms of family characteristics, there were urban and rural differences in family income (US \$1 = 48 Taka) ( $t = -2.39$ ,  $P = .02$ ) and in mothers' level of education ( $\chi^2 = 5.74$ ,  $P < .02$ ).

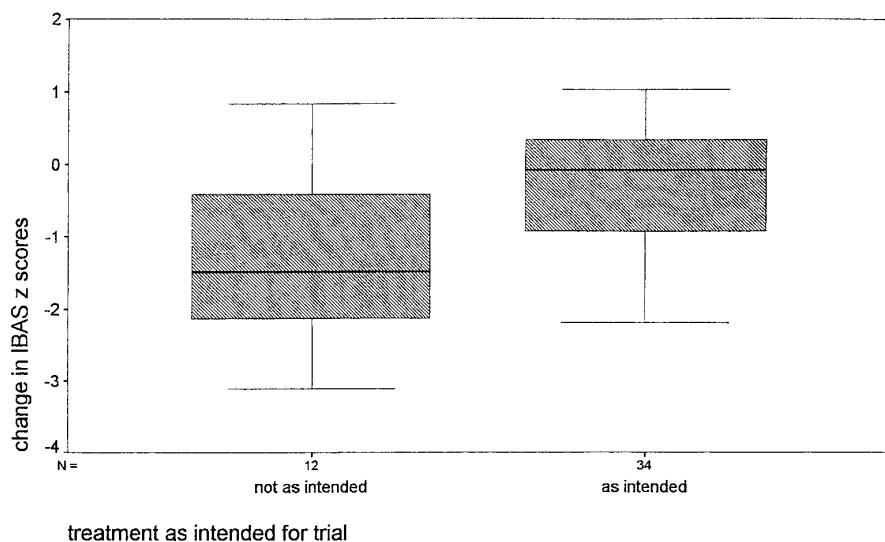
However, within samples, there was only one significant difference in child and family characteristics: between the rural distance training package and health advice groups in the proportion of families who were landless (distance training, 63%; health advice, 25%;  $\chi^2 = 4.29$ ;  $P = .04$ ). Therefore the randomization seemed in general to have produced equivalent study groups demographically.

There was a considerable difference across groups in terms of the interval between first and second assessment ( $F(3,54) = 2.80$ ,  $P < .05$ ), with several of the families allocated to the mother-child group having been particularly difficult to contact for a follow-up assessment. Each of the following analyses of change was therefore checked again, taking interval into account in the calculation.

### *Change Over Time*

For the *rural* groups, it was hypothesized that children whose parents received active intervention with distance training packages would progress better in adaptive skills than those receiving only health advice (Table III). The predicted pattern of change was found: in the health advice group there was a significant decrease in rate of progress compared with the norm (ie, mean IBAS *z* scores dropped from initial to final assessment ( $t = 2.78$ ,  $P < .02$ )), and not in the distance training package group. For the latter, there was a small, non-significant decline in *z* score, and this meant that the degree of change was not significantly different between groups. The fact that the distance training package group was more disadvantaged in terms of the majority having no land may have lessened the positive effect of intervention.

It was further hypothesized that the level of maternal stress would decrease and maternal adaptation to the child, perceived levels of support, and assessed knowledge would increase for the distance training package group, with no such changes in the health advice group. The predicted pattern was found for mothers' perceptions of the helpfulness of formal sources of support, which increased significantly for the distance training package group ( $t = -3.25$ ,  $P < .01$ ). When change scores were compared directly between the rural groups, the intervention group showed significantly more positive change ( $t = 2.77$ ,  $P < .02$ ). Both the distance training package group and the health advice group reported increased maternal adaptation by the end of the study (having been significantly lower than that of the urban mothers before intervention,  $F(3,54) = 11.58$ ,  $P = .00$ ). Apparent reductions in stress were not significant, and there was no change in parental knowledge. Therefore the hypothesis of differential change between groups was not supported for 3 of the 4 maternal variables in the rural sample. One possible explanation is the



**Fig 2.** Difference in rate of progress in children's adaptive skills depending on whether therapy was received as intended (box plot showing median, minimum, maximum, and interquartile range).

low power of the study, given the degree of variability in, for example, stress levels before the study (overall mean, 6.38; SD, 5.02).

For the *urban* groups, the null hypothesis was proposed in terms of differential change, and this is what was observed for all measures. Furthermore, it was expected that an effect of intervention would be seen from initial to final assessment in both groups. In terms of children's adaptive skills, z scores did not decline significantly, which may imply a small intervention effect (by comparison with the rural health advice group).

For mothers in the mother-child group, there was a significant increase in knowledge ( $t = -2.96, P < .02$ ), and there was some increase in knowledge for mothers in the distance training package group. There was also an increase in perceived helpfulness of formal sources of support, which just missed significance in the case of the mother-child group ( $t = -2.63, P = .025$ ). Maternal adaptation to the child increased in both groups, significantly so in the mother-child group ( $t = -2.87, P < .02$ ). However, stress levels rose on average in both groups after intervention, though not statistically significant-

ly. Thus observed changes for mothers in both urban groups were in the direction predicted for a positive intervention effect (somewhat more consistently for the mother-child group) with the exception of maternal stress.

### Attendance As Intended

There was considerable variation in the degree to which mothers were willing or able to return to the clinic bases to take part in the intervention programs. Attendance at the distance training packages service was for a mean of 6 sessions (Table II), but only 11 (of 16) urban mothers and 12 (of 19) rural mothers returned for 4 or more of the intended 9 times. Those allocated to the mother-child group attended for a mean of 24 times. In all, 34 (of 46) mothers had a minimum of 4 contacts with therapists and said they had used the training package manual (distance training package groups only) at the post-program interview; this was taken as a definition of "therapy as intended." There was a significant difference between those who received therapy as intended and those who did not in terms of positive outcome for the child's skill development; that is, the former showed, on

average, no decrease in the level of their IBAS z scores between initial and final assessments ( $U = 107, P < .02$ ), which implies they were matching the age-normed rate of acquisition of new skills (Fig 2). There was a trend for rate of development of new skills to be related positively with increase in maternal adaptation ( $r = .26, P < .08, n = 46$ ).

## DISCUSSION

Two studies of disabled children, one in Guyana<sup>7</sup> and one in Egypt,<sup>27</sup> have shown quantitative differences in children's skill attainment, depending on the mode of delivery of services, and the importance of fully involving mothers. We have established evidence of the effectiveness of an outreach program for young children with cerebral palsy through brief training of mothers, who were given pictorial manuals to take home. All of the children in the present study were young with a diagnosis of cerebral palsy, and more than 40% had severe motor disability; therefore, dramatic progress in adaptive skills was not expected. However, positive effects in maintaining the rate of children's skill development were shown in the active intervention groups, particularly when mothers did bring their children for the program several times.

The mothers attending the mother-child group, who had the most contact with therapists, significantly increased their knowledge of how to help a disabled child. More urban than rural mothers had had education and so may have been better able to absorb didactic experience and use knowledge conveyed on paper. At the post-program interview, several rural mothers mentioned that they had lost the distance package training manual (eg, in a flood). Within the intervention groups, progress in children's adaptive skills was associated with increased maternal adaptation, as has also been shown

**Table III.** Changes over time

	Urban		Difference between urban groups in mean amount of change (95% CI)	Rural		Difference between rural groups in mean amount of change (95% CI)
	Distance training group	Mother-child group		Distance training group	Health advice group	
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
IBAS z scores						
Total						
Pre	-2.62 (1.13)	-2.04 (1.54)		-2.10 (1.81)	-1.77 (2.01)	
Post	-3.11 (1.10)	-2.75 (1.62)	-0.22 (-1.02, 0.57)	-2.61 (2.40)	-2.50* (2.25)	0.21 (-0.61, 1.02)
Adaptation to the child (Judson scale)						
Pre	109.88 (15.11)	112.18 (15.94)		90.68 (13.94)	86.92 (10.47)	
Post	113.69 (15.73)	122.18* (12.61)	6.19 (-3.78, 16.15)	109.84* (17.55)	121.00* (12.99)	-14.93 (-30.99, 1.14)
Stress (SRQ)						
Pre	4.44 (3.12)	4.45 (3.75)		7.79 (5.77)	7.08 (4.93)	
Post	6.75 (4.64)	6.00 (4.71)	-0.77 (-4.94, 3.40)	5.74 (4.47)	3.83 (4.37)	1.20 (-3.60, 6.00)
Parental knowledge						
Pre	8.47 (1.64)	8.05 (1.96)		8.13 (1.98)	8.21 (1.70)	
Post	9.94 (1.88)	10.55* (2.67)	1.38 (-0.93, 3.69)	7.89 (1.74)	8.21 (1.29)	-0.24 (-1.67, 1.20)
Family Support Scale						
Informal						
Pre	13.88 (6.65)	12.73 (7.09)		13.05 (8.99)	15.73 (5.14)	
Post	15.25 (7.38)	13.45 (6.46)	-0.65 (-5.75, 4.45)	14.63 (7.72)	15.91 (6.89)	1.58 (-4.90, 8.06)
Formal						
Pre	3.19 (4.32)	2.18 (2.18)		1.11 (2.11)	1.91 (3.30)	
Post	4.06 (3.70)	4.36 (4.20)	1.31 (-1.31, 3.93)	4.00* (4.42)	0.82 (1.17)	4.09† (1.00, 7.19)

IBAS, Independent Behaviour Assessment Scale; Pre, before intervention; Post, after intervention.

\*Significant change from pre-intervention to post-intervention assessment,  $P < .02$ .

†Significant difference between the rural groups in amount of change,  $P < .02$ .

in developed countries.<sup>10</sup> Thus there was evidence of broader effects of intervention, not just on the child. However, the models of intervention examined in this evaluation focused primarily on the child and did not directly address families' wider problems.<sup>8</sup> For positive effects to become self-sustaining, it might be important to harness support of the other members of the family by including home visits. The results provided no evidence of change in perceived helpfulness of informal sources of support to mothers, such as neighbors, relatives, or coworkers.

Intervention may have had paradoxical effects. Participation increased stress for a considerable proportion of mothers, particularly those coming to the urban clinic. Attendance was variable, and distance and transport were frequently mentioned as problems.<sup>28</sup> In addition, though maternal adapta-

tion to the child did increase on average, it was enhanced most for the health advice group. It may be that the "minimal" health advice and box of toys intervention, with a request to come back in 9 months' time, was found reassuring by parents and took emphasis away from the child's disability. Conversely, there may be an emotional cost for mothers in attempting to participate in distant services, which are hard for them to access, increasing their frustration in being unable to help their child consistently, having made the original efforts to find a source of useful advice. Similar apparently paradoxical effects of intervention on parental adaptation have been noted in a study of children with epilepsy in West Bengal.<sup>29</sup> Thus providers of services need to consider both potential positive and potential negative effects of any intervention and to minimize stress on parents. For

example, a community-based rehabilitation service might be considered, merging outreach developmental services with support to the family more generally.

In conclusion, the trial indicates that an outreach parent training service (distance training packages) in a country such as Bangladesh shows promise in helping mothers to improve the skills of their young children with cerebral palsy. However, it is suggested that services should be widened to include family support to mothers, reinforced through home visits.

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