

## ABSTRACT

### PARENT-TO-PARENT OUTREACH FOR FAMILIES OF INFANTS WITH DOWN SYNDROME

The purpose of this proposal is to develop an outreach program staffed by volunteer parents, themselves parents of a child with Down syndrome, intended to provide support, caring and basic information to newly identified families of Down syndrome infants. The proposal is based on the assumption that parents can offer other parents many things a professional lacks (eg., a special kind of empathy, a shared viewpoint); but that without proper training, the most well-meaning efforts can go awry. The program will be administered through PROUD by a volunteer Parent Outreach Coordinator (POC). The program itself will consist of several components:

1) Actual parent training: An 8 hour skill-building workshop for interested parent volunteers which will include presentation of a) the grief cycle b) therapeutic core qualities c) listening skills d) common mistakes e) problem-solving difficult situations f) limits of parent outreach. The workshop will also provide each participant with a list of appropriate agencies and networking resources serving families and children with Down syndrome. The emphasis of the workshop will be on role-play and group discussion, with a necessary amount of didactic material included. The workshop will strongly encourage couple participation and training, while ensuring that every participant can function effectively as an independent intervener. The workshop will also be geared to dealing exclusively with parents of infants with Down syndrome, which will allow greater specificity and concreteness in development and presentation of materials.

2) In addition, each parent who participates in at least one outreach encounter will have the opportunity to attend up to 3 "booster" sessions throughout the year. These sessions will be small-group oriented (approximately 6 people) and last about 2 hours. The intent of these sessions is to examine in detail specific problems and dilemmas which arise as a result of outreach, and consider alternative ways of responding. They are also designed to provide support for the volunteer parents.

3) The proposal contains an evaluation component, which will allow PROUD to assess on an ongoing basis the effectiveness of the program, and modify its interventions accordingly. Both volunteer parents and newly identified families will be interviewed briefly and respond to questionnaires in order to better understand both strengths and weaknesses of the program. Parent training will then be modified accordingly.

## GOALS FOR THE YEAR

- 1) Completion of three training sessions for a total of 50 parents
- 2) Translation of parent training materials into Spanish
- 3) Access to 3 "booster" sessions during the year for all parents who have made at least one outreach visit
- 4) Evaluation of training sessions
- 5) Evaluation of parent outreach encounters
  - a) completion of one feedback interview with each parent who has received outreach
  - b) completion of one follow-up phone call for evaluation purposes 3-6 months after the initial contact
  - c) completion of brief assessment questionnaire by every parent who has received outreach
- 6) Completion of approximately 35 initial parent contacts throughout the year; completion of an average of 5 additional contacts for each original family
- 7) Dissemination of information about infants with Down Syndrome to approximately 40 new families; and dissemination of Spanish-language training materials to the Spanish Down Syndrome Club
- 8) Preparation of a summary report which can be used as a model in the development of similar parent outreach programs