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DEAF PATIENTS AND CHILDREN: AN INNOVATIVE ORGANIZATION BY AND FOR DEAF PARENTS

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Abstract

Parents and Children (PAC) is both a support group and organization. This is an organization that provides support to families in which one or both spouses are hearing impaired. These families also include children who are either deaf or hearing. What began in Rochester, New York, as an informal parent group early in 1985 evolved to the present formal PAC organization three years after its inception. This paper attempts to describe how PAC started, to explain the goals and purposes of PAC, to outline the types of programs offered and, finally, to point out why such a support group should be modeled in other communities where deaf and deaf/hearing parents of deaf/hearing children are located.

Historical Overview of PAC

The idea for this organization began with one mother's desire for an informal parent support group and the efforts of a local pastor who had been involved with pastoral counseling for the Rochester deaf community. In April of 1985, a young deaf couple was sent to the pastor by a family court judge for family counseling. Out of concern for the young people, the judge and social worker asked the pastor if there was any kind of group for deaf parents of young children. At that time, nothing was available. To help meet the needs of the mother, and of the deaf people, the pastor proceeded to contact a few families to see if some type of informal group could be started. A small group of four families met informally for potluck dinner and social interaction. Since that first informal interaction, the original group of four families grew into a formal organization. Even though a local pastor initiated the group, the activities provided were never regarded as a "ministry" of the church. However, church facilities were made available for social and educational meetings.

The following year (1986) marked the first year of operation as a formal organization. President Howard Mann remarked at a 1986 Open House: "Most of our own hearing parents formed support groups for Hearing Parents of Deaf Children to obtain moral support among each other. As a result of their support group, they learned how to raise us, their deaf children, to prepare us for the future as members of society." He further added: "I believe the same idea applies to us as deaf and deaf/hearing parents." Thus, meeting together enables parents to appreciate the fact that they are supporting and learning from each other and especially helping each other develop positive experiences in raising their deaf/hearing children. PAC members were reinforced of the need and purpose of this organization.

During the first year of the organization, the support group was called Hearing-Impaired Parents and Kids (HIPAK), but after deliberations among officers, the name was changed to Parents and Children (PAC) to reflect the intention of those the organization wished to serve. It was important for the organization name to reflect not only deaf parents but deaf/hearing parents as well as the wide range of age groups of children.

Goals/Purposes of PAC

The purpose and goals of Parents and Children (PAC) were developed and approved by several families during the first year of its inception. The listed goals are straightforward and oriented toward proactive education and parental support.

1. To function as a support group to help deaf and deaf/hearing parents with deaf/hearing children to learn and develop appropriate and effective skills in raising their children.
2. To provide peer support among deaf and deaf/hearing parents to help them learn from other parents how they are able to resolve

DEAF PATIENTS AND CHILDREN: AN INNOVATIVE ORGANIZATION BY AND FOR DEAF PARENTS

- problems experienced while raising their children.
3. To provide peer support among hearing children of deaf parents to help them accept and understand that they are not the only ones who do not have hearing parents (e.g., hearing friends may ridicule his/her hearing parents because of his/her deafness).
 4. To allow social and personal interaction among deaf/hearing children and deaf and deaf/hearing parents.
 5. To gain enrichment experiences as parents of deaf/hearing children through seminars, lectures, workshops or group discussions.

Characteristics of PAC Membership

There are currently 37 families who are paid members of PAC. Of the 37 families, there are six couples in which one spouse is a hearing person. Looking into the composite make-up of the 37 families, there are 64 children whose ages range from two months to 18 years of age. A majority of the children's ages are between four and seven. Of the 64 children, 57 are hearing and seven are deaf. PAC members pay a nominal yearly fee which covers cost of guest speakers, art supplies for children, and educational materials for parents.

Board membership includes a President, Vice President, Recording Secretary, Corresponding Secretary, Newsletter Editor, and an Activities Chairperson. Since this organization is still relatively new, written by-laws are in the developmental stages. Board members hold office for a two-year term with election occurring during the Fall when PAC begins the new year.

Description of Group Activities

In order to provide specific activities matching our listed goals, PAC board members devised and distributed a two-page questionnaire to the membership during the Spring of 1986. As a result of responses from the questionnaire, a comprehensive program of specific activities for both parents and children was developed. For the year 1986-1987, PAC alternated monthly social and educational activities. Examples of social events offered during that year were: Fall Open House, Parents/Children Halloween Party, and Parents/Children Chanukkah-Christmas Party. Educational seminars/workshops offered during that year included: Developmental Stages of a Normal Child; Discipline from the Dreikurs

Perspective; What is Diphtheria, Pertussis and Tetanus and its Risk; and a panel discussion with Deaf/Hearing parents of Hearing Children. Evaluations of many of the above activities were rated positively. In reading the evaluation summary for the Deaf Parent Panel discussion activity – participant responses included comments such as: “I learned about how to deal with communication issues with hearing children;” “listening to the panelist helped me clear a lot of old misconceptions about deaf parenting role;” “I learned to develop a better understanding of deaf/hearing relationships.”

During some of the PAC-sponsored events, it has been noticed that parents function as a support group for each other. Parents would often talk about issues of raising children, or offer tips/suggestions to parents experiencing new situations in dealing with their children. This kind of information-exchange activity occurs as a natural situation without the formality of PAC. Because of the common interest among members of PAC, it became a natural phenomenon to be talking about their positive or challenging experiences in their parenting role with children. For example, at a recent general meeting, two parents were exchanging information about local day care/preschool centers while two other parents were discussing successful toilet training tips. Other parents were also observed discussing communication challenges with children.

Additional Features

PAC publishes a quarterly newsletter which is distributed to paid members. This newsletter serves as the main vehicle for sharing information about upcoming events, and exchanging information on how parents can use their parenting skills to raise their child. The newsletter features a book review column discussing parenting books and books related to deaf/hearing issues. Personal stories as well as other articles of interest printed by other PAC members are also included. The editor (and co-author of this article) plans to expand future editions to include interviews with experienced deaf parents, young hearing children and other hearing children. The newsletter attempts to incorporate articles of general child-rearing issues as well as issues specifically related to deafness. Members who are not able to attend specific education functions benefit from reading the newsletter.

An added feature PAC provided included an

DEAF PATIENTS AND CHILDREN: AN INNOVATIVE ORGANIZATION BY AND FOR DEAF PARENTS

experimental six-week Dreikurs Parent Study group for PAC deaf and deaf/hearing parents. Dreikurs Family Education Association of Rochester is a non-profit, non-denominational organization which espouses the Dreikurs approach to parenting. Dr. Dreikurs and colleague Dr. Alfred Adler advocated a positive approach to raising children – encouraging them, building on their success, not their failure, improving their self esteem and involving them in solving problems and making decisions at an early age. The study group proved to be very successful. With minor modifications, the Dreikurs Parent Study group activity will be expanded to include more PAC members. One of the deaf participants is interested in becoming a trained Dreikurs Parent Study group facilitator in the hopes of reaching out to more deaf parents. Additionally, a four-week workshop on “How to Talk to Kids So Kids Will Listen, and Listen So Kids Will Talk” was offered to PAC members. Due to the success of this activity, a follow-up workshop will be offered.

Summary and Recommendations

Effective parenting roles and skills can be viewed as a major and important job in teaching and guiding children for positive adjustment and accommodation to American society. The added challenges to parents who are deaf/hearing impaired include being able to learn up-to-date information on raising their own children, being able to learn to deal with communication issues with their own children, and helping their own children understand the challenges of having hearing-impaired parents.

The positive experiences and successful activities demonstrate that a need for support group and deaf/hearing parents of hearing/deaf children is a high priority. Use of this kind of organization can be modeled in other communities where deaf and deaf/hearing parents of deaf/hearing children are located because wide diversification of learning experiences may be encountered while raising children. For example, parents may be faced with issues dealing with parenting skills such as: developing knowledge of appropriate discipline of children; increasing understanding of personal and social skills development of children; and learning how to help children acknowledge and accept having deaf parents with unique communication needs.

The recommended strategy for successful implementation of this model for a support organization for deaf and deaf/hearing parents is outlined below.

1. Interested families should start out with informal activities (i.e., potluck social gatherings). The key organizers should try to get the feelings of interest among families who attend and discuss if there is a need and desire to establish a formal organization or informal support group.
2. Select individuals to form a planning committee to focus on the implementation and development of a formal survey to identify the needs and nature of program offerings/activities. The questionnaire should cover areas related to parental issues, kinds of activities and/or seminars that should be planned for both parents and children. The survey design and dissemination is an important process. The planning committee should consider including a cover letter identifying the rationale for a support group organization of deaf parents.
3. After the collection of the questionnaire and data interpretation of the survey from interested families, the next suggested plan is to share feedback of the survey results and to decide on either an informal support group or a formal organization. If a formal organization is desired, it would then be appropriate to have an election of officers to begin the first organization term of a formal organization.
4. The elected officers of the formal organization would then need to appoint different standing committees according to the needs identified from the survey. Examples of standing committees can include: social planning committee, children’s activities committee, workshop/seminars planning committee, and child care/chaperones committee.

In conclusion, this organization is seen as a viable and necessary support for deaf/hearing parents of hearing/deaf children in the Rochester, New York, area. It is the authors’ hope a similar concept can be modeled in other communities where deaf and deaf/hearing parents are located. Parents as well as children receive a much needed support.