

## Ability to Pay Workgroup

### Report for December 8, 1999 VICC Meeting

Although the Workgroup has not met, we have corresponded regularly via e-mail and the phone. Activity has taken place on several items.

After the last VICC meeting, we sought clarification of the statement in the department's written report to the VICC that findings support Old Dominion University's overall observation from the (Family) Survey that monthly payment rates did not highlight a need for program adjustment. This was confirmed to be inaccurate. ODU's responsibilities did not include making recommendations. In addition, in my role as ATP Workgroup co-chair, I continued to seek data from the Department about locality-specific family survey results. With the help of another workgroup member, Carmen Sanchez, and her husband Rob Gibbs, we were able to access locality-specific family survey results from my original data file. It provided more detailed data to help us understand the breadth and depth of the ATP problem.

A meeting was held to discuss the data; participants included ATP Workgroup members, Management Team members, Babies Can't Wait staff, Mike Lupien, from the DMHMRSAS Office of Research and Evaluation, and the ODU Family Survey researcher. The group reached consensus on the following points:

- It is unknown how many surveys were actually given to families. Jeff Harlow reported that the actual number could not be determined because after a telephone survey of council coordinators, it was discovered that a significant number of the coordinators did not know the actual number of surveys they distributed to families.
- 621 families responded to the Family Survey. 422 families reported they pay at least \$1.
  - Of the 422 fee-paying families who responded, 83 families indicated that they chose not to receive some or all recommended services.
    - 31 of these 83 families indicated that the reason they chose not to receive the services is that the fees charged for the services were beyond affordability.
    - These 31 families were served in approximately 14 different councils representing a wide geographic and size distribution.
    - The 31 families represent a wide range of income levels.
    - ***Given the geographic and economic variations of the 31 families, the choice to not receive services because they are beyond affordability could be a systemic issue.***

There was not consensus concerning what other conclusions could be drawn from the data or whether the data leads to specific solutions.

In early November, I was asked by Steve Waldron, Executive Director of the ARC of Virginia, to organize an ATP Workgroup presentation to the HJR 725 Joint Subcommittee Studying EI Services. The meeting was well-attended and several family members spoke about their experiences and their perspectives on the problem. Family comments from the Family Survey and the Focus Groups, as well as letters from families who were unable to attend the meeting, were distributed. The subcommittee members indicated interest in forwarding a Joint Resolution to alert the General Assembly to this problem. Martha Adams, Director of Mental Retardation Services, answered a question from Delegate Christian about what is going to happen to resolve this problem. She reported that a group has formed to work on resolutions and she expects this to be on the fast-track. I was informed that the Deputy Commissioner, Cathleen Newbanks, had met the prior day with Steve Waldron of the ARC and involved department staff.

Several families have expressed interest in seeing the continued involvement of the families and providers who have worked so long and hard on this issue as members of the Workgroup. This problem is very complex, and there are no easy fixes now apparent. The Workgroup will meet after the VICC meeting is over. Other interested parties are invited to attend.

Hand-outs from the subcommittee meeting will be available at the VICC meeting, and they are also available via e-mail. We recently received the final family focus group report (Ability to Pay for Early Intervention Services: Family Perspectives). It is (or will soon be) posted on the Virginia Babies Can't Wait web site.

It's very interesting, and is also available upon request. Please contact me at Emily1RFR@aol.com or 804-977-0432 if you would like more information. Thank you for your interest and support.

*Submitted by*

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