

**CQI Workgroup on Part C Fees
And
Ability to Pay**

**Meeting Summary
Henrico CSB – Conference Room C
July 20, 2000**

Those attending: Sheila Null, Anne Simmons, Liz Hutton, Christa Shifflett, Wanda Pruett, Shirley Ricks, Liz Fletcher, Emily Dreyfus, Glen Sönneger, John Jackson, Forrest Mercer, and Mary Ann Discenza

Those absent: Joel Rothenburg, Joy Yeh, Martha Adams, Joan Pine, Anne Lucas, Joe Sharrer, Geri Pratt, Patti Seklemian, and Barry Mason

The following comments were made about the June 14, 2000 meeting summary: (text in italics and bolded are the changes that were made to the meeting summary).

- Change the bullet on page 1 under the heading dealing with pertinent points from the presentation about the draft document *Part C Policy* to read as follows: ***Ability to pay relates to consumers for whom the full cost of service presents a financial hardship.***
- Page 2, first bullet on the page; ***Discussion ensued about state requirements that families must state that the fee is a financial hardship before the family can access the fee scale and providers are obligated to state the full charges for services.***
- Page 2, the third bullet; The *Guiding Principles* seek to define ***a less burdensome more equitable fee system.***
- Page 2, the eighth bullet; ***Discussion ensued about whether most boards are taking families to zero fee.***
- Page 3, the fifth bullet on the page; ***Specific suggestions from two of the participating agencies were discussed and will either be incorporated into the Guiding Principles, or followed up with the agency.***
- Page 3, number 6; ***Planning presentation to the Agency Heads, reviewing information to be presented.***
- Carmen Sanchez requested that the workgroup add her resignation letter to the meeting record for June 14, 2000. After a brief discussion, the request was duly noted and the letter added to the meeting record.

Discussion occurred around the dissemination of meeting summaries to workgroup members including timeliness of feedback related to changes desired by specific members to ensure accuracy of reporting about the content of the meeting. The

workgroup agreed that while it was important to disseminate information to the field, it was equally important to ensure that process provided for consensus building around issues the workgroup confronted. In order for full participation of members, consensus of members included the following:

1. Draft meeting summaries will be e-mailed and/or faxed to members.
2. Members will review meeting summaries and feedback/comments may be sent to staff in order to make necessary changes and modifications to the draft document.
3. Meeting summaries will be discussed and approved at the next meeting and only then forwarded to the BCW Office for publication on the BCW web site.

The next order of business involved a discussion of a fourth hypothetical fee scale that was developed by a sub-committee comprised of John Jackson, Emily Dreyfus, and Christa Shifflett. Explanation about the fourth fee scale was presented; the methodology used to develop the scale and a handout of data showing the financial impact of the scale on a family of four was discussed among workgroup members. Pertinent points about the scale: allowable amounts, e.g. net income after deductions and depending on family income and size, parameters that included reasonable and consistent factors; within the constraints of the Code; etc. Additional points included: hidden savings accruing due to decreased administrative costs, productivity savings, is there support for a budget amendment if an amendment were necessary, etc. Concerns were expressed about the impact of this scale on private providers and whether or not the scale was marketable to the Agency Heads. In order to determine if additional state funds might be necessary as well as to provide solid data about the fiscal impact of implementing the new scale, there was consensus about measuring the financial impact over a six-month period post implementation. A suggestion was made for a simple tracking tool. After reviewing the information presented, there was consensus about the concept and members agreed to accept the scale and made a recommendation for the scale to be presented to Commissioner Kellogg for guidance and direction.

There was a brief update about the private provider survey. Concerns were expressed about localities' ability to meet the deadlines for data submission. Christa reported that members of CoCoA had expressed a number of concerns related to workload issues and anticipated poor response rate from private providers. There was agreement that a checklist should be developed to track responders and that there would be follow-up phone contact in order to ensure information would be collected from as many private providers as possible. The suggestion was made to ask staff in Research and Evaluation to suggest a "reasonable response rate". Shirley agreed to check with Mike Lupien and others for a response. After considerable discussion there was consensus about the following point: the workgroup would stick to the deadlines and would be happy with the data that we get, even if this means that there is not a high response rate.

The remainder of the meeting involved a discussion of the draft document entitled *Part C Early Intervention Program for Infants and Toddlers with Disabilities Ability to Pay*

Practices. Some of the preliminary changes have been made to the draft document based on the recommendations from the workgroup and John J. and Emily D. agreed to meet or phone one another to work out additional language in one section of the document. The revised draft will be disseminated with the final meeting summary of the July 20, 2000 meeting. John Jackson, Wanda Pruett, and Shelia Null agreed to develop a packet for families to be given to families entering the Part C system.

Another agenda item involved discussion about the VICC recommendation on special instruction. (Please refer to copy of letter from the VICC chair about this specific issue.) There was agreement that a letter should be sent to the VICC indicating that the workgroup was researching this recommendation and a response would be made in the near future.

The final item involved discussion about issues for the Commissioner's meeting scheduled for July 27, 2000. Consensus from the workgroup: meet with Commissioner Kellogg to market the proposed fee scale and ask for guidance about next steps.

Items remaining for consideration:

1. The Sliding Fee Scale package needs to be refined.
2. Strategies need to be developed for disseminating the information including developing and planning training events for service coordinators, fiscal officers, reimbursement staff, private providers, local council representatives, parents, etc.
3. Based on the outcome of the meeting with Commissioner Kellogg, determine next steps.

Reminder: the meeting with Commissioner Kellogg is scheduled for July 27, 2000 at 10:00 AM and will be held in the 13th floor conference room at DMHMRSAS. There will be a business meeting after the Commissioner's meeting.

June 15, 2000

Dear Liz,

I am resigning as co-chair and as a member of the CQI Workgroup on Ability to Pay and Part C Fees. Although my walking out of yesterday's meeting may have looked like a hasty decision, I have considered resigning for quite some time now, and the comments made by the Commissioner (as communicated by Shirley and Mary Ann) and John Jackson at the committee meeting confirmed the conclusion that I had already reached: if I want to work towards meaningful change in the fee system for Part C services, my energies are better spent exploring other options than participation on this workgroup. As you know, I have repeatedly expressed my frustrations with the work of this group, both in the meetings and in e-mails, and although our roles as co-chairs was meant to address some of those issues, I think that the major underlying issues about our purpose and our ability to suggest meaningful changes remain intact. Before leaving Dodge, however, I would like to explain how yesterday's comments confirmed my conclusion that my energies are better spent elsewhere. I cannot, nor do I wish to, speak about the Commissioner's and John Jackson's motives or thoughts, and I respect their opinions, which arise from their knowledge and considerable experience. Of course, the Commissioner is obligated to run the department as he best sees fit and at the pleasure of the Governor. However, as a citizen of the Commonwealth, as an advocate, and as a parent of a child with a disability, I have to decide for myself how I can best serve all parents in the early intervention system.

First of all, there is a profound difference between my approach to the ATP issue and the approach to the same issue as expressed by the Commissioner. Shirley stated at the VICC meeting that the Commissioner wanted to remind us that the Department's role is to address the needs of the poor and (by implication) not the needs of the middle class. Now, this may be true of all other programs housed in DMHMRSAS, but as an entitlement, Part C services are for all families, regardless of income. Services that are mandated by law to be free, such as service coordination, must be free to children living in shacks and Bill Gates' children equally. Therefore, Part C services are most akin to Part B services, which must all be provided as part of a free and appropriate public education. The fact that DMHMRSAS houses Part C because of the historical decision to make the Department the lead agency does not in any way change the nature of Part C, but it does make it a very different program within the department. Furthermore, by its very nature, Part C is about early intervention to prevent further developmental delays in children, and in some cases get rid of the delays altogether, so isn't it in keeping with this philosophy to set up fee systems that prevent families from losing their middle-class status because of fees? Moreover, from the get-go, I have stated that the middle-class families are the most affected by family fees, and my work on this committee has stemmed from that premise, even as I have worked diligently to protect poor families from burdensome fees. The family survey shows that fees affect families of all social classes, and this workgroup was put together, in my understanding, with the pervasiveness of this issue across classes as a given.

The implications of seeing the ATP issue in terms of protecting the poor and not in terms of providing affordable services for all incomes -- and specifically preventing the middle-class from moving down the economic scale because of the cost of services -- are obvious in John Jackson's revisions to the documents generated earlier by the committee. The revised documents, in essence, keep in place the current system that requires that families prove their inability to pay (through, in Wanda's phrase, "a strip search") in order to be eligible for the more generous fees. John made a reasoned argument for why such procedures are in keeping with his experience with the juvenile and adult system, and therefore the necessity to keep this process consistent with that, but the argument is built on a faulty comparison between the other programs in DMHMRSAS and Part C, as I have outlined above. But he is also right that in order for the sorts of changes to go through as outlined in the original documents, a change in the Code of Virginia is necessary. I believe that it is highly unlikely that this workgroup will recommend changes in the Code, and therefore the recommendations will tweak the current system but not address the central issues. As I have stated before, I am not interested in engaging in such limited discussions.

The Commissioner's comments about his and the Department's obligation to serve the poor, and the need for low-income and diverse parent participation on the workgroup, trouble me deeply. First of all, this is the first time that I have heard the Commissioner express that his obligation is primarily to low-income families in relation to this issue. I reread his report to HJR 725, and nowhere in either his comments on the ATP issue or about Part C issue in general is the issue of economic class brought up. In fact, on page 6, he specifically refers to families sharing their concerns and the impact of the fees on these families' lives, but nowhere is there a discussion of the families' economic class, and many families who testified clearly identified themselves as middle class. Why the sudden shift in focus on this issue as it impacts low-income families?

Secondly, I am distressed that now, six months in to the work of the workgroup, the Commissioner is expressing his desire to have more parents on the workgroup. As I stated at the VICC, when the workgroup started, parent participation was clearly limited: the ARC of Virginia was to assign two parents to the committee (Wanda and Emily), and the VICC ATP workgroup could assign two members, one of which had to be a private provider. It's only because the VICC ATP workgroup chose me as the other representative that I even got on this workgroup. In December, I would have done everything possible to get more parents on the workgroup from as many different geographic, ethnic, and socio-economic backgrounds as possible. Furthermore, in December, no one asked any of the parents on the workgroup if they represented diverse opinions, so why ask now?

Implicit in this request, too, is a sense that middle-class parents cannot properly represent the interest of parents of all social classes. Yet, if this is true, than how can the Commissioner or anyone else in the Department truly serve the interests of low-income families if they themselves are middle-class? Furthermore, how is it that as a Hispanic woman, I do not bring some ethnic diversity to this group? If the Commissioner wants a diversity of parent opinions brought to bear on this issue, then why is it that he will not

allow workgroup members to share, one on one, the materials developed by the workgroup with a wide and diverse group of parents? I have no problems with adding parents to the workgroup now, and I made a point of asking Sheila Null to join us, but why change the rules of engagement six months into the game?

Again, I refer you to my earlier, long e-mail about this workgroup's purpose and whether workgroup members have the authority to make recommendations and work through our ideas to their logical conclusions. Nothing that has happened up to this point, six weeks after the original date for completing our work, has led me to believe that this workgroup can function effectively to make real and significant recommendations to solve the issues with ability to pay scales and fees. Therefore, I respectfully resign from this workgroup. My work on my local council as the Family Resource Coordinator, and on the state level as the editor of Family Matters, on the MIMS Task Force, and as a member of the General Supervision & Finance subcommittee of the OSEP Monitoring Part C Steering Committee is sure to keep me busy with early intervention issues.

Carmen Sanchez