

Virginia Interagency Coordinating Council Meeting June 9, 1999

Attendance: See the attached list of VICC members and guests.

The meeting was called to order at 9:40 by Cherie Takemoto, Chair. Minutes of the March 10th meeting were approved after correction of the agency listing for Leslie Anderson.

Beth Tolley gave a follow up report on the **Action Items** from the March VICC meeting. A copy is attached.

Nominating Committees

Beth Tolley reported that candidates are still needed for parent and provider **representatives to serve on the VICC.**

Pat Abrams, Jim Blackman and Betty Williams volunteered to serve on the nominating **committee for officers.**

Council Coordinators Association

Christa Shifflett reported on the newly formed Council Coordinators Association. Three work groups have been formed including one to serve as a liaison to the Virginia Association of Community Service Boards, one for natural environments, and one for development of bylaws. The next meeting is June 11 in Charlottesville. Topics include grant writing and alternative funding sources.

Announcements and Expressions of Appreciation

Cherie Takemoto announced that Kathy Maggio has resigned from the VICC. Leslie Anderson has taken a new job in a new agency and thus will no longer serve on the VICC as the representative from the Department of Social Services. Cherie expressed appreciation from the VICC to Kathy and to Leslie for their dedicated service on the council.

Cherie Takemoto thanked Anne Lucas, Beth Tolley and others involved in making the special VICC meeting on Natural Environments a success. Handouts from the meeting are available from the Virginia Babies Can't Wait office.

Cherie thanked Richard Corbett for the outstanding job he did on the Annual Report.

Cherie expressed great appreciation to the members of the Ability to Pay Work Group for the intensive and extensive work they have done.

Richard Corbett asked that folks who are interested in serving on the VICC Administrative Committee contact him.

Cori Hill announced that the Family Support and Advocacy Committee is looking for provider members. Interested persons are to contact Cori.

Presentation by Barry Mason and Terri Tuck: See attached report

Public Comment: See attached report

Information from Don Kates (NEC*TAS): See the attached report

Presentations by the Ability to Pay Work Group

Summary of the Issues

Carmen Sanchez presented a summary of the issues related to ability to pay. See attached copy.

Family Survey

Tancy Vandecar, Old Dominion University, presented the results of the family survey. The preliminary report is attached. One significant finding is that all families, not just middle class families are having difficulty affording services.

Family Focus Groups

See the attached report for results of the focus groups that were conducted by VIDD.

Ability To Pay Work Group Report

A copy of the Ability to Pay Work Group Report is attached. Mary Ann Discenza reported that the results of the survey and focus group validated the information the work group had received from council coordinators about families leaving early intervention because of fees. See the attached copy of the report

Discussion

Families should be informed up front of fees and procedures. Waiting for families to ask before using the ability to pay scales causes unnecessary delays.

Cherie Takemoto stated that we need to take action now. She expressed concern about the assurances that we have provided to the Federal Government about families not being denied services due to inability to pay.

Cherie expressed thanks to the Ability to Pay Work Group for bringing the data forward. She stated that if we fail to act now, "we are making those babies wait."

Leslie Anderson summarized findings of the studies:

1. Families are leaving Early Intervention
2. Families are declining some services
3. There are significant inconsistencies in charges to parents

Ann Cox reminded the group that there is a 4th category of families who never get to the Early Intervention System.

Jim Blackman, MD stated that the current system is either not fixable or is very difficult to fix. There are inconsistencies and unfairness across the state. He suggested looking into the feasibility of providing early intervention services without fees. Careful study of the potential financial impact would need to be done prior to recommending that there be no fees for services. Legislation would be needed to require insurers to pay for services for which families are not charged fees.

Use of available funding sources other than family fees (as opposed to "free entitlement") is recommended. Brenda Laws suggested the following:

- Enforce families not being charged more than they can afford
- Service Coordinators advocate for families (family rights)

Bev Crouse stated that it is difficult for service coordinators who are employed by CSBs to advocate for families to their employer. Beth Reed Treadway expressed concern that service coordinators are being expected to do more and more and that caseloads are increasing resulting in much needed work not being completed.

One issue that arises with insurance is the state law requirement that co-pays be collected. In some cases this results in families paying more than they would if they were on the sliding fee schedule.

Anne Lucas clarified that as we work to resolve the issues related to inability to pay, we need to look at the model of service provision as well as the fees.

Susan Shaw asked if state funding would be available to localities if the localities develop "reasonable fee scales."

Steve Waldron stated that a consistent, statewide ability to pay scale could have regional differences. A change in the code would be required. The earliest this could be accomplished would be during the 2000 General Assembly. There are two issues:

- Changing the law
- Obtaining additional funding

There must be data to substantiate the need. In addition, families must get behind this and speak up.

Allan Phillips stated the equity issue must be addressed immediately. It was stated that an equitable ability to pay schedule is irrelevant if the charges for services are vastly different. Caps on fees charged might provide more equity.

Anne Lucas reported that in Utah, there is a movement to provide more consistency across the state; this is resulting in a more state-driven system than they had.

Jim Blackman made the following proposal:

I move that the management team develop a legislative or other administrative proposal for a statewide equitable, family friendly sliding fee schedule for early intervention services. Some remedial action should be implemented as soon as possible.

Furthermore, that the management team explore whether certain non-reimbursable early intervention services could be exempted from fees to families (in addition to assessment, child-find, and service coordination) such as special instruction, respite, transportation services.

The motion was seconded and passed by the VICC members in attendance (Rose Singleton, Leslie Anderson, Liz Hutton). Remaining VICC members will be polled individually. The proposal will be addressed at the July Early Intervention Interagency Management Team meeting.

The meeting was adjourned at 3:00 PM.

Addendum: VICC members were polled as planned. The proposal passed unanimously.

**Virginia Interagency Coordinating Council
June 9, 1999
Attendance**

VICC Members:

Elizabeth Hutton	VDH
Anita Cordill	DMAS
Helen B. Byrd	NSU, Personnel Preparation
Rose Singleton	Parent
Glen Slonneger	DVH
Shirley Ricks	DMHMRSAS
Cherie Takemoto	Parent, VICC Chair
Pat Abrams	DOE
Betty Williams	Parent
Jim Blackman	UVA, Personnel Preparation
Barbara Mease	The Children's Center, Provider
Leslie Anderson	DSS, VICC Secretary

Speakers/Presenters:

Barry Mason	DMHMRSAS
Terri Tuck	DMHMRSAS
Don Kates	NEC*TAS
Tancy Vandecar	ODU
Patrick Shannon	VIDD
Carmen Sanchez	Parent, ATP

Guests:

Anne Lucas	Virginia Part C Coordinator		
Beth Tolley	Virginia Babies Can't Wait!		
Richard Corbett	Virginia Babies Can't Wait!		
Beverly Crouse	Virginia Babies Can't Wait		
Mary Ann Discenza	Virginia Babies Can't Wait		
David Mills	Virginia Babies Can't Wait		
Muriel Felder	Cultural Diversity Specialist	2210 Osbourne Rd. Chester, VA 23931	
Mary Lou Hutton	CICC	PO Box 810, Cedar Bluff, VA 24609	(540) 964-6702
Janie Shoup	Mt. Rogers ICC	440 W. Ridge Road Wytheville, VA 24382	(540) 223-3270
Jane Prince	Eastern Shore ICC	PO Box 70 Belle Haven, VA 23306	(757) 442- 7599
Mary Ann Mummet	Step by Step	800 Preston Ave. Charlottesville, VA 22903	(804) 970- 2150

Beth Reed-Treadway	Step by Step	800 Preston Ave. Charlottesville, VA 23903	(804) 970- 1391
Steve K. Waldron	ARC of Virginia		
Nancy Wilson	ARC of Virginia	2090 Strawberry Run Crozier, VA 23034	(804) 784- 2337
Alexis LaMenthone	ARC of VA		(804) 649- 8481
Allan J. Philips	Fairfax		(703) 246- 7120
Brenda Crockett	Chesapeake		(757) 547- 8929
Ellen Powers	Va Beach Infant Program	2307 Millwood Road Virginia Beach, VA 23454	(757) 437- 6241
Sandy Hermann	Parent	5881 Glen View Drive Virginia Beach, VA 23464	
Christa Shifflett	SVICC	209 W. Criser Rd, Suite 200 Front Royal, VA 22630	(540) 636- 4592
JoAnne Lamkin	Parent, SVICC	1419 Canterbury Road Front Royal, VA 22630	(540) 635- 2193
Carmen Sanchez	Parent	3750 Old Lee Highway Fairfax, VA 22030	(703) 319- 0621
Sheila T. Cox	Parent	Rt. 2, Box 406 Pounding Mills, VA 24637	(540) 963- 0832
Karen Myers	Project Daniel, Lynchburg		
Anne Simmons	Central Virginia ICC	2235 Landover Place Lynchburg, VA 24501	
Tina Beachy	Harrisonburg/ Rockingham EIC	1241 North Main St. Harrisonburg, VA 22802	
Cori Hill	H-R CSB Pace	1241 N. Main St. Harrisonburg, VA 22802	

Deana Buck	RIC	VCU Box 843020 Richmond, VA 23233	
Alison Standing	Rappahannock ICC	600 Jackson Street Fredericksburg, VA 22401	(540) 899- 4347
Linda Dwyer Geri Pratt	Western Tidewater Parent The Chesapeake Ctr.	1417 N. Battlefield Blvd. Suite 142, Chesapeake, VA 23320	
Sharon Sikes	Children's Hospital	2924 Brook Rd. Richmond, VA 23220	
Susan Shaw	Blue Ridge Infant & Toddler Council	PO Box 5392 Charlottesville, VA 22905	
Emily Dreyfus	Parent Chair, ATP	1201 Little High Street Charlottesville, VA 22902	
Janine Stegall	Regional Family Representative	20692 Rainsboro Drive Ashburn, VA 20147	(703) 729- 6046
Ann Cox	VIDD	Box 843020, VCU Richmond, VA 23284	
Pat Rogers	The Chesapeake Ctr.	6506 Louisdale Rd. Springfield, VA 22150	
Beth Sarrett	The Austin Program of Virginia	6 North 6 th Street, Suite 403-A Richmond, VA 23219	
Diane Evans	HICC	266 W. Valley Street Abingdon, VA	(540) 623- 8000
Darlene Warsing	NWCSB Parent Infant Education	Mt. Royal, VA	(540) 636- 4592
Lynn Ruiz	Arlington Council Coordinator	1810 N. Edison Arlington, VA 22207	(703) 349- 0058
Catherine Burzio	SVICC parent		
Rosalind Cutchins	Western Tidewater Coordinator		

VICC (Virginia Interagency Coordinating Council) Meeting (June 9, 1999)
Attachment

Presentation by Barry Mason and Terri Tuck

Key Issues:

- Each agency or provider sets their own fees and fee scales
- There is great variety in the process and in the scales

Community Service Boards (CSBs) must abide by the Code of Virginia and by State Board Policy.

- According to the Code of Virginia, CSBs must charge for the services they render, but the Code does not dictate how to charge (i.e., by service or by time unit or by event). Each CSB develops their own policy related to charges. The Code of Virginia applies to the CSBs and to facilities under the jurisdiction or supervision of CSBs. For private providers contracting with CSBs, the language of the contract determines whether the provider has to follow the Code.
- According to State Board Policy, each CSB must have a policy about ability to pay. Specifics are not dictated. The result is 40 CSBs with 40 different policies.

Fees are specific to each CSB and are usually based on direct costs plus indirect costs plus overhead. The cost of providing services is often more than the fee charged for the service. CSBs are supposed to charge what it costs to provide the service, but that is not being done consistently across the state.

There should be a fee appeal process in place. There are procedural safeguards in the CSB system to assure that families are informed of their rights.

An attempt was made in 1990 to standardize fees, but there was so much opposition that the Commissioner halted the process.

The CSBs are under mandate now through the new performance contracts to be aggressive in developing contracts with third party payors.

The **State Health Department** has one sliding fee scale that is used statewide, though it has adjustments built in for cost of living in some areas of Virginia.

Fees paid for early intervention services do not necessarily go back into the revenue stream for early intervention; allocation of those fees depends on how the CSB sets up its budget. Fees collected for early intervention in the Health Department go into the county or city general funds. *As a state, we do not know the amount of revenue that is collected for early intervention services.*

Federal Regulations require that Part C be the payor of last resort. The states must determine which services will require fees (not including those mandated to be free). Part C is working with the private providers to expand networks.

There is a distinction between inability to pay and refusal to pay. Terri Tuck stated that refusal to pay stems from agreeing on a level of responsibility, then not living up to the agreement. Sandy Herman, parent, asked how the determination is made that there is an inability to pay versus a refusal to pay. She said, *How do I tell my daughter we can't take you to swimming classes because we have to take your sister to therapy?"*

Carmen Sanchez, parent, stated that we are four years into the implementation of fees and that she has heard numerous horror stories. Some councils have just now established an appeals process. She asked for an interpretation of equity of fee scales. She stated that some families are going into bankruptcy after the child is

out of Part C, when the child is five or six years old. *AWhat you (the family) prayed would go away turns out to be a lifetime condition.*@

There was a discussion about whether the issue was one of folks not knowing the process for appeals and whether the process was followed versus an issue of inability to pay.

Steve Waldron reported that some folks are reluctant to appeal. He gave an example of a favorable outcome when the service coordinator followed up and facilitated the process of fee appeal. He stated we are dealing with two issues - the ability to pay issue and the issues in the service system of monitoring families so that families do not get into the position of dropping out of services due to fees.

Cathy Burzio stated that there is a 40 - 1 ratio of families to service coordinators in some places. We may need to reduce the number and may need support to do that.

Nancy Wilson said that it is embarrassing for families to say they can't afford the services their child needs.

Geri Pratt echoed the comments of Steve Waldron of the ARC. She said they recognize the councils, programs, and providers who have made extreme efforts to help families. Training of service coordinators and quality assurance are critical. Geri named the following examples of Programs who have worked hard to meet the needs of families: Virginia Beach, Chesapeake Infant Intervention Program, Henrico County, Chesterfield County, Middle Peninsula, Warren County, Northwestern.

Rose Singleton stated that there is an issue of what is considered allowable and what is not when determining ability to pay. When we know that early intervention is cost effective, the fact that people are not getting services demonstrates that something is wrong.

Shirley Ricks stated that we must work to make the system work. Service coordinators must be working with the CSBs, must be knowledgeable and must advocate for their clients.

Wanda Pruett stated that children should not be penalized by the bad decisions of their parents, which is the case when parents choose to spend their money on things other than early intervention services for their children.

Christa Shifflett stated that families start out paying full fees. The moment the family says they can't afford the fees, the appeal process is started. The Reimbursement Office in their CSB (Shenandoah) handles this.

Cherie Takemoto asked if any CSB could decide that the required payment would be capped at \$50 instead of the charged amount of \$1700, for example, if the parent says that \$50 is all they can pay. Barry Mason said that could happen.

State laws supersede VICC for the CSBs. A legislative code change would be required for VICC to make requirements of the CSBs.

Shirley Ricks cautioned that the VICC not jump to legislative action without considering other solutions.

If legislative action is recommended, the information/request must go to the state agencies before September. Cherie Takemoto recommended that VICC take action today in order to meet this time frame.

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Attachment

Public Comment:

Each guest introduced himself/herself. See attendance list.

Nancy Wilson stated that *Awe at the Association for Retarded Citizens (ARC) are willing to play any role we can to resolve the issue of finances impacting access to services.*

Beth Reed-Treadway commented that there is a difference between inability to pay and refusal to pay.

Cori Hill read the following statement: *I'm Cori Hill and I'm the Infant Program Director in Harrisonburg and Rockingham County. Recently our CSB has proposed an increase in rates for infant education/special instruction from \$5 per visit to \$30 per visit. I am here to represent two sides of the ability to pay issue. The first is my local CSB-s concerns regarding this issue. In a memo dated 2/16/99 from Barry Mason to local council coordinators, CSB executive directors, CSB reimbursement staff and Part C regarding special instruction and fees, Mr. Mason states that instruction is a clinical service and CSBs must charge fees. If fees are not charged, DMHMRSAS Office of Reimbursement will cite CSBs.*

From the Infant Program Director-s point of view, I understand the CSB-s concerns and I certainly would not want to be cited by anyone for anything. However, how do I justify to families in my program the cost of special instruction at a high rate and not billable to insurance with conflicting rates for PT and ST that, for most families, will cost less due to insurance and co-pays. We will be eliminating our consultative approach and returning to a more medical model. Our costs for therapies will skyrocket due to increased demand. Families may opt to discontinue services because services will be free when their child turns two.

My question: When are the department, the Part C office and Medicaid going to collaborate and complement each other to assist us in providing appropriate services to families?@

Steve Waldron reported that he has been working with legislators. He says Virginia has an excellent service system for infants and toddlers and their families. He has told legislators that they should look at the Early Intervention system as a model for the adult system. A problem in the service system for infants and toddlers is the need for Medicaid to be a much bigger player. Excellent collaborative relationships are essential to help improve services. He is willing to help in any way he can.

Janine Stegall, Parent to Parent Representative, read a personal statement from **Jo Anne Smith McKey**, Coordinator, Parent to Parent of Arlington and Alexandria.

In the spirit of participation with the VICC in its efforts to assess the impact the fee system has had on Virginia families, I appreciate this opportunity to express some of the concerns I have around the Ability to pay@ issue. Specifically, I have serious concerns about the impact of the fee system on middle to upper middle class families who find themselves at the top of the fee scale.

I facilitate support groups for parents of children with disabilities in both Arlington and Alexandria. In both groups, I have worked with middle class parents who have been faced with having to make choices about which service and/or therapy they felt they can afford for their child enrolled in the PIE program.

Because of the structure of the fee systems in both jurisdictions, middle class families are hit hard. Therapies cost \$80- \$93 per session at full fee. (Families whose adjusted income is \$50,000 or more are at full fee). If the child receives only one therapy per week, the cost per month is over \$300.00. Families tell us they do not have that few extra hundred dollars per month to pay for services. Or their child needs more than one service, doubling their potential outlay per month. Parents, seeing precious savings and cash reserves flowing out, have to make terrible choices. Thus begins the vicious cycle of guilt (for having to deny their child something

he needs because of their inability to pay), and anger at the system for not making it economical for their child to receive the service. In the end, family supporters like me, and others who work with the local ICC, are caught in the middle, trying to support families and guide them through the bureaucratic morass. The system is unfair to a middle class family, struggling to make ends meet, that has to pay full fee for services that other families get for free. Aren't both families struggling, relatively speaking? This disparity in treatment is troubling and taxes our ability to remain credible with families who ask *Why?* This untenable situation with the fee scale has given rise to many sad conversations with parents. Recently a parent asked me if I was still in my same house, or had I had to sell it to pay for therapies (she and her husband were considering the idea). Another family glumly talked about having to file for bankruptcy. A mother called me the other day to say she had refused services from the local PIE program, because, at the top of the fee scale, they pay less to a private provider, even with the local jurisdiction's 5% cap. She explained that she was told that the county ran its cap from January to December and because she was referred in June, the cap didn't help her family! It was more economical for her to get services for the child outside the service delivery system. There was a family who declined cognitive therapy because their insurance would not reimburse the costs, and the cost of the therapy was beyond their budget.

The law mandates that no child will be denied services because of inability to pay for them. This tenet is not stretching over to the over-stretched middle class! Some of our families are making decisions to accept or decline services based purely on economics. This is wholly unfair to them and to their child.

I implore the VICC to do something now, today, to address this problem. It's true Babies Can't Wait... not another year, not another legislative session for change to occur. Take a stand for families now. We can do better.

Sincerely,

Jo Anne Smith McKey, Coordinator, Parent to Parent,

Alexandria/Arlington

Janine also stated that she had been asked, *What is the VICC going to do for families?* She said she falls in the middle class category; she made sacrifices and was aggressive in getting her needs met.

Emily Dreyfus reported that the Ability to Pay Work Group has been working since November 1997. The group appreciates the opportunity to present their findings today.

Glen Slonneger asked if it is possible that a family would have to file for bankruptcy to be able to pay for early intervention services. He questioned if the appeal process would kick in before that happened.

There was a discussion about whether the issue was one of folks knowing the process for appeals and whether the process was followed versus an issue of inability to pay. All are issues.

Sandy Herman, parent, asked how the determination is made that there is an inability to pay versus a refusal to pay. She said, *How do I tell my daughter we can't take you to swimming classes because we have to take your sister to therapy?*

Terri Tuck responded that refusal to pay stems from agreeing on a level of responsibility, then not living up to the agreement.

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out of Part C, when the child is five or six years old. *What you (the family) prayed would go away turns out to be a lifetime condition.*@

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Nancy Wilson said that it is embarrassing for families to say they can't afford the services their child needs. Geri Pratt echoed the comments of Steve Waldron of the ARC. She said they recognize the councils, programs, and providers who have made extreme efforts to help families. Training of service coordinators and quality assurance is critical. Geri named the following examples of Programs who have worked hard to meet the needs of families: Virginia Beach, Chesapeake Infant Intervention Program, Henrico County, Chesterfield County, Middle Peninsula, Warren County, Northwestern.

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Information from Don Kates, NEC*TAS representative

The following must be provided at no charge to families:

- child find
- evaluation and assessment
- development of IFSP
- service coordination
- procedural safeguards

Federal regulations state that IFSP services are to be free to families unless state or federal regulations have provisions for a sliding fee schedule. Fees can be charged so long as they don't prevent families from receiving services. Families can appeal the charges. Families can choose not to purchase services.

With traditional private insurance policies, there is a contract between the insurance company and the family. The policy indemnifies (that is, protects) the family against certain costs they'd have to pay if they did not have the insurance. The insurance company has no obligation to pay for services that are free to the family. The contract usually does not cover services provided by the government.

HMOs protected the insured person against all costs at first. Now they are falling into the same category as private insurers.

Part C money can be used to reimburse families for co-pays or deductibles.

IF insurance is used to cover services that are not billed to families (with policies that allow for this), we must be aware that this may cause an increase in premiums in the future that may affect the amount of money available later if the insurance has a lifetime cap on payments.

Don Kates provided information about how several other states are financing early intervention services.

Maryland has a "birth mandate." Infants (from birth) are covered by Part B. There is never a cost to the family. There is very little insurance coverage for early intervention services in Maryland. There is nothing that prevents them from billing insurance **but** once there is cost to family, the billing must stop.

Massachusetts has a state operated early intervention system. \$3200 of the cost of early intervention services per year must be provided by any insurance plan that is regulated by the state.

5-10% of early intervention services funded by private insurance. This allows them to stretch federal money.

Part C always pays the co-pay or deductible for the family.

Connecticut has a \$5000/yr. cap on cost for services/ per year for three years. Dollars spent for coverage of early intervention services do not count toward the child's lifetime insurance cap. Connecticut has a state operated fee scale. It is used to determine families' ability to pay for co-pays and deductibles.

Don reported that, in many states, fee scales are in place but not used. Some providers do not want to bother with collecting fees from families.

Don stated "no state can run its program on the fees it collects."

Virginia's direct funding contribution for Part C services is small. 40-45 states provide more state funding for EI services. Pennsylvania and Texas have the most state funding.

Indiana does not have fees for services. They planned to have fees, but due to negative feedback, decided not to. They set up a mandatory system of financial case management.

If there are no fees to families, it is hard (or impossible) to collect for third party payers

If a company is self-insured, it cannot be regulated by the state. They are exempt from legislative mandates. (In Virginia, 60% are self-insured; 40% of the insurance companies fall under the mandate). The companies can elect to cover the mandated services. Key employees need to lobby for the desired coverage.

New York has an insurance mandate. Their mandate exempts early intervention from lifetime maximums or caps. Families do not pay fees for services in New York.

The following questions were raised:

- Can the code be amended to require insurance payment even for those services for which families aren't charged?
- What specific services insurance companies are not covering?
- How can we help family whose insurance is self- insured

It was suggested that one of the safeguards to families is a standard fee schedule and standardization of what is considered when determining "ability to pay." However, fee schedules cannot be regulated unless the federal law is changed.

Don Kates stated that there is nothing to prevent amending the insurance mandate bill to require that early intervention services be covered even if there is no charge to families. States that do not charge fees build their funding structure to include Medicaid, state appropriations, DD, the Education system and other interagency systems.

Only 5 states have an insurance mandate.

Medicaid requires other 3rd party payers be used first.

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Carmen Sanchez provided the following summary of the issues:

Commitment to serving all families

- *best for children and families*
- *best for the future of families*
- *gives meaning to "family-centered" practice*

Fee issue in light of IDEA

- *serving all families regardless of income*
- *poor families are served, but middle class is squeezed out*
- *child find and child count affected by families opting out because of fees, thereby reducing the effectiveness of child find efforts*

Families opting out because of fees

- *families in affluent areas going to private providers and never knowing about EI*
- *families in less affluent areas getting no services at all because no providers*
- *families in areas waiting until 2, when child can enter schools, thereby undercutting promise of EI families not even going to screenings or MDEs because they have heard fees too high.*

Problems confronting our work centered on definition of "ability to pay"

- *definition of "ability to pay" highly subjective and not at all uniform even within economic classes, professionals, parents*
- *term "ability to pay" implies judgment of parents, which is problematic in light of past economic choices which bear on present economic choices parents make, differing value system in regard to valuing services, guilt parents feel about children's disabilities*
- *economic choices by parents of children with disabilities are seen in light of a lifetime of economic obligations to children (and suggests providers are speaking out of both sides of their mouths when asking parents to confront disabilities yet charging exorbitantly for services).*

"Ability to pay" should be practically and philosophically divorced from issues of judgment

- *focus on the law, making sure that family fees are not barriers to any family receiving needed services*

What the evidence shows

- *studies are not representative but their validity lies in the absolute numbers, what they tell us about families that have not been served*
- *over 80 documented cases in service coordinator records of families in the year time frame opting out of services all together because of fees, with slightly over 1/2 the councils reporting.*
- *more than 100 families reporting on survey that they opted out of services altogether or reduced services because of concerns for fees.*
- *family stories in focus groups about financial hardships and even bankruptcy because of fees*
- *administrative data that shows fees are the luck of the geographic boundary family lives in.*
- *inconsistent or nonexistent appeals procedures*

Where do we go from here?

- *top priority to assure that fees do not prevent families from receiving the services they need*
- *consistent fee scales that don't leave families at the mercy of geography*
- *consistent appeal mechanisms that allow for a family's fee to be -0-*
- *demographic data analysis that uses all forty councils' administrative data on family income that would show the extent of the vanished families.*
- *somewhere, because for many families we are nowhere*

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Speakers/Presenters:

Barry Mason	DMHMRSAS
Terri Tuck	DMHMRSAS
Don Kates	NEC*TAS
Tancy Vandecar	ODU
Patrick Shannon	VIDD
Carmen Sanchez	Parent, ATP

Guests:

Anne Lucas	Virginia Part C Coordinator
Beth Tolley	Virginia Babies Can't Wait!
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Muriel Felder	Cultural Diversity Specialist	2210 Osbourne Rd. Chester, VA 23931
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Mary Lou Hutton	CICC	PO Box 810, Cedar Bluff, VA 24609	(540) 964-6702
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Janie Shoup	Mt. Rogers ICC	440 W. Ridge Road Wytheville, VA 24382	(540) 223-3270
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Jane Prince	Eastern Shore ICC	PO Box 70 Belle Haven, VA 23306	(757) 442- 7599
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Mary Ann Mummet	Step by Step	800 Preston Ave. Charlottesville, VA 22903	(804) 970- 2150
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Beth Reed-Treadway	Step by Step	800 Preston Ave. Charlottesville, VA 23903	(804) 970- 1391
Steve K. Waldron	ARC of Virginia		
Nancy Wilson	ARC of Virginia	2090 Strawberry Run Crozier, VA 23034	(804) 784- 2337
Alexis LaMenthone	ARC of VA		(804) 649- 8481
Allan J. Philips	Fairfax		(703) 246- 7120
Brenda Crockett	Chesapeake		(757) 547- 8929
Ellen Powers	Va Beach Infant Program	2307 Millwood Road Virginia Beach, VA 23454	(757) 437- 6241
Sandy Hermann	Parent	5881 Glen View Drive Virginia Beach, VA 23464	
Christa Shifflett	SVICC	209 W. Criser Rd, Suite 200 Front Royal, VA 22630	(540) 636- 4592
JoAnne Lamkin	Parent, SVICC	1419 Canterbury Road Front Royal, VA 22630	(540) 635- 2193
Carmen Sanchez	Parent	3750 Old Lee Highway Fairfax, VA 22030	(703) 319- 0621
Sheila T. Cox	Parent	Rt. 2, Box 406 Pounding Mills, VA 24637	(540) 963- 0832
Karen Myers	Project Daniel, Lynchburg		
Anne Simmons	Central Virginia ICC	2235 Landover Place Lynchburg, VA 24501	
Tina Beachy	Harrisonburg/ Rockingham EIC	1241 North Main St. Harrisonburg, VA 22802	
Cori Hill	H-R CSB Pace	1241 N. Main St. Harrisonburg, VA 22802	

Deana Buck	RIC	VCU Box 843020 Richmond, VA 23233	
Alison Standing	Rappahannock ICC	600 Jackson Street Fredericksburg, VA 22401	(540) 899- 4347
Linda Dwyer Geri Pratt	Western Tidewater Parent The Chesapeake Ctr.	1417 N. Battlefield Blvd. Suite 142, Chesapeake, VA 233220	
Sharon Sikes	Children's Hospital	2924 Brook Rd. Richmond, VA 23220	
Susan Shaw	Blue Ridge Infant & Toddler Council	PO Box 5392 Charlottesville, VA 22905	
Emily Dreyfus	Parent Chair, ATP	1201 Little High Street Charlottesville, VA 22902	
Janine Stegall	Regional Family Representative	20692 Rainsboro Drive Ashburn, VA 20147	(703) 729- 6046
Ann Cox	VIDD	Box 843020, VCU Richmond, VA 23284	
Pat Rogers	The Chesapeake Ctr.	6506 Louisdale Rd. Springfield, VA 22150	
Beth Sarrett	The Austin Program of Virginia	6 North 6 th Street, Suite 403-A Richmond, VA 23219	
Diane Evans	HICC	266 W. Valley Street Abingdon, VA	(540) 623- 8000
Darlene Warsing	NWCSB Parent Infant Education	Mt. Royal, VA	(540) 636- 4592
Lynn Ruiz	Arlington Council Coordinator	1810 N. Edison Arlington, VA 22207	(703) 349- 0058
Catherine Burzio	SVICC parent		
Rosalind Cutchins	Western Tidewater Coordinator		