

DHR/DPH

Babies Can't Wait

PUBLIC HEARINGS Report

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Note: Remainder of report includes Babies Can't Wait proprietary and confidential information, and it has been deleted from this electronic copy.



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Executive Summary

The Babies Can't Wait (BCW) program is Georgia's statewide early intervention system for infants and toddlers with special needs, ages birth to three, and their families. The Department of Human Resources (DHR) Division of Public Health (DPH) is the lead agency for administration of the BCW system. In 2007, DHR conducted an examination of the BCW system to make sure it was performing well and was sustainable. To meet federal requirements and ensure there was maximum stakeholder input, the public was strongly encouraged to participate in a 60-day public comment period regarding proposed revisions to the Georgia Babies Can't Wait Standards.

During the public comment period of June 18 to August 20, 2007, a series of public hearings was held in each of the 18 public health districts in Georgia. This report presents a compilation of comments received at the public hearings, which were facilitated and recorded by Care Solutions, Inc., an independent consulting firm. The "Common Themes" sections of this report also include a review of written comments sent to the BCW state office by mail, e-mail or fax during the comment period. (A separate appendix contains the written public comments sent directly to the BCW state office.)

Comments that were common across all hearings and written comments centered on these major themes:

- Satisfaction with/importance of BCW early intervention services; implication of budget or service cuts in the long term
- Implication of budget cuts in the short term
- Lack of clarity regarding the proposed changes
- Elimination/change of Service Coordinator function
- Therapists acting as Service Coordinators
- Managed care organizations acting as Service Coordinators
- Doctors being required to sign IFSPs
- Comprehensive Child Find System and Children 1st as point of entry
- Managed care issues driving providers out of the system, decreasing access to services
- Change in service model & procedures
- Regional challenges

Some of these themes related directly to the revised standards while others did not. Among the issues that related to revised standards, the most prevalent comments concerned the service coordinator position. In addition to high praise for existing service coordinators, most people who commented had numerous questions and concerns about therapists and/or CMOs acting as service coordinators. Another area which received a significant number of comments was service delivery, with most concerns centering on providers leaving the system, causing lack of service availability in many areas.

The wide range of issues expressed was probably due to several factors, including admitted confusion about the revised standards and the desire to express opinions on other pressing issues. Among the latter, there was extensive comment about problems allegedly caused by CMOs regarding reduction of services, denial of services, and delayed and non-payment for services. One respondent summed up the prevailing opinion of many with the question, *“How can you marry medically-driven insurance companies that have a profit-making mentality with an educationally-driven BCW program, mandated by federal law, whose bottom line is to provide support to children and families?”*

In general, the written comments sent to BCW (mail, e-mail, fax) reflected somewhat greater understanding of the revised standards than comments at the hearings. Among both groups, those who appeared to be more knowledgeable about the standards expressed concern that the revisions did not help solve the existing problem of consistency among districts, but rather made consistent implementation of BCW practices almost impossible and staff training more difficult. Overall, several commented that the standards did not address the key issues facing BCW with regard to sustainability and efficiency, and in some cases did not reflect the principles of Part C of the Individuals with Disabilities Education Act (IDEA).

Beginning on page 5, this report presents two sections which report “Common Themes” across all public hearings and with regard to the revised standards, respectively. Keeping in mind the factors stated above, it is important to consider *both* sections when attempting to get a true picture of the results of the public comment process.

Introduction/Process Overview

Babies Can't Wait (BCW) is Georgia's interagency early intervention system for coordinating and assuring that young children (ages birth to 3) with developmental delays are receiving health, developmental and educational services to develop optimally, including services to the family. The Georgia Department of Human Resources (DHR) Division of Public Health (DPH) is the lead agency for administration of the BCW system. In early 2007, DHR completed an examination of the BCW system to make sure it was performing well and was sustainable. Proposed system changes resulting from this examination were developed, including proposed revisions to the Georgia Babies Can't Wait Standards. A public comment period was held from June 18 to August 20, 2007.

The proposed revisions to the Georgia Babies Can't Wait Standards (*Introduction and Revised Standards: Child Find, Evaluation and Assessment, IFSP, Service Coordination and Service Delivery*) were distributed and publicized statewide during the public comment period. The proposed revisions were posted on the Division of Public Health main web page (<http://health.state.ga.us>) and on the Babies Can't Wait web page (<http://health.state.ga.us/programs/bcw/>). Hard copies of the proposed revisions were also placed in multiple locations throughout each public health district (at least one location per county). A sign-in review sheet was included with each copy for use by any citizen who reviewed the document.

Written comments on the proposed revisions were accepted by the BCW state office via mail, e-mail or facsimile. Additionally, citizens were able to comment verbally or in writing at a series of 18 public hearings, one held in each district. Care Solutions, Inc., a private agency, served as the facilitator and recorder of the public hearings and is the author of this report.

Public notice of the placement of the standards for review and the public hearings was provided statewide beginning July 1, 2007. Babies Can't Wait district staff notified families and providers via mail, fax and/or e-mail. State office staff disseminated information about the public comment period and public hearings to state agencies, community organizations, advocacy organizations, therapy associations and to various other potentially interested groups. The DHR Office of Communications disseminated a news release/public announcement to the Georgia Press Association. District Public Information Officers were asked to follow up with local media and to place additional notices at local community and faith-based organizations with targeted outreach to agencies and organizations serving minority families and children.

The hearings were held in each of the state's 18 public health districts from July 26 to August 9, 2007. BCW district staff greeted citizens who attended and asked them to sign in and indicate if they planned to speak at the hearing and/or provide a written comment. Two Care Solutions staff attended each hearing to facilitate and record/accept comments.

Summary of Common Themes Across All Public Hearings and Written Comments Submitted to Babies Can't Wait

The 18 scheduled public hearings in Georgia were completed between July 26 and August 9, 2007. Participants expressed several common themes which were fairly uniform across both rural and metro areas. Many of these same themes were reflected in the written comments sent to the BCW state office. While some of the themes/comments do not relate directly to the proposed standards for which the hearings were held, they were consistently expressed in most locations and thus reflect the sentiments and concerns of the hearing participants.

Satisfaction with/importance of BCW early intervention services; implication of budget or service cuts in the long term

- Parents, without exception, agreed that they had witnessed the enormous positive impact that early intervention services had with regard to their children's disabilities.
- Local relationships and stability have been important to the success of the BCW program.
- Children who are under-served as infants or toddlers cost the state and federal government more money later on -- both as students and as adults with special needs.
- Without early services, some children will be lower functioning citizens than they could be and/or require lifelong public assistance to function.
- Until the advent of managed care organizations and the changes regarding Medicaid reimbursements, BCW was functioning well and expanding services on behalf of children/families in need.
- Even with the agency's funding difficulties, the work of BCW was praised.
- Proposed changes in the program are prompted by monetary concerns and do not take needs of families and children into account.
- School systems will incur increased special education costs if early intervention services are not provided adequately in years 0-3.
- Carving BCW children out of care management organizations (CMOs) would prove more cost effective in the long run.

Implication of budget cuts in the short term

- There is doubt that proposed changes will actually result in lowered expenses for BCW.
- The service coordination function will still have to be paid for, whether it is done by existing coordinators, therapists or CMOs.
- If CMOs attempt to increase profits by denying services, services must still be provided by BCW because of its federal mandate (this is happening already), causing BCW budget overages.

Lack of clarity regarding proposed changes

- Standards are broadly stated and need to be re-stated or explained in order for proper comments to be made; respondents do not understand what changes in standards mean for changes in practice.

- Confusion was expressed over who to contact for more information at state office due to staff turnover.
- As taxpayers, voters, and parents, people expressed that their input should have been sought before changes were proposed.
- The information is not clear; need for information meetings on proposed new standards and their implications for services (for both providers and families).
- Confusion expressed about resource coordinator position vs. service coordinator position; if resource coordinator is housed at BCW, it appears to transfer responsibility back to BCW without additional funding being provided.
- Will there be a phase-in of new standards, vis-à-vis families already in the current system?
- Families (as well as providers and staff) expressed concern about being unable to get answers regarding the nature of and timetable for changes.
- Families were concerned about losing current therapists and/or services.

Elimination/Change of Service Coordinator function

- Service coordinators are the core of the BCW program.
- The service coordinator is an experienced and highly trained position; how could this be replicated by someone who is trained for and doing another job?
- If independent service coordinators are eliminated, there will be no neutral party to defend/obtain needed services for children.
- Service coordinators provide objectivity as well as anonymity.
- Service coordinators know the community and are therefore able to connect families to additional resources even outside of their medical needs.

Therapists acting as Service Coordinators

- Therapists are not trained to be service coordinators.
- A conflict of interest is possible if therapists also function as service coordinators.
- Could therapists legally write IFSPs without specialized training?
- Therapists are too busy to add service coordination to their duties; it would overwhelm them.
- Therapists will not take on these extra duties if the pay stays the same.
- All important tasks provided by service coordinators could not be fully shouldered by therapists.
- What recourse does a parent have if there are problems with the therapist and that person is acting as the service coordinator?
- Therapists will not have the knowledge and/or resources to assist families dealing with grief, depression, marital stress, problems with siblings, etc.
- Will therapists have to cancel appointments to take children/families to transitional meetings?

Managed care organizations acting as Service Coordinators

- The service coordinator job is extensive and requires local knowledge and face-to-face contact with the families; CMO staff, acting by telephone from a distance, could not do the job well.
- Concern was expressed about CMO staff being trained per federal regulations.
- There was concern about CMO staff being both service coordinator and gatekeeper for funds, an apparent conflict of interest.
- Using a CMO as a case manager/service coordinator would be detrimental to the children and their families due to the fact that staff would probably never meet the family/child in person.
- Staff turnover at CMOs is a concern for ongoing liaison with families, since the service coordinator position requires regular contact with family, service providers and primary care physicians.
- Will CMOs send staff to the meetings, such as IFSP meeting, six-month review and required annual review?

Doctors being required to sign IFSPs

- Waiting for physician's input/signature will delay service; many doctors fail to complete the current paperwork obligations within specified time limits.
- Problems already exist with timely communication between BCW and doctors' offices; doctors do not have time to add new requirements/paperwork to their schedules.
- The end result will probably be delay of or reduction in needed services to children.
- Doctors may decide to drop Medicaid patients altogether if they have more administrative burdens placed on them.
- Have the physicians been asked if they have time to be more involved?

Comprehensive Child Find System and Children 1st as Point of Entry

- Children 1st is slated to take a more active role in performing developmental screening; respondents were not sure how Children 1st is going to be able to handle this duty considering they have had a tremendous staff cut-back.
- Even with Children 1st as the single point of entry, BCW will not be able to meet the federally suggested benchmark of 2 percent of the birth-to-three population if the turnover rate of BCW staff continues to increase.
- Children 1st and BCW need to be on the same page regarding consistency in handling referrals if Children 1st is to be the front door point of entry for all new referrals from the Division of Public Health.
- Referral guidelines with regard to Children 1st are not clear; how will they be staffed and paid to handle referrals?

Managed care issues driving providers out of system, causing decrease in services

- Managed care organizations have onerous paperwork requirements, requiring repeated re-submission of paperwork due to submissions lost at the CMOs and minor variances in filling out forms.
- Managed care organizations reimburse therapists very slowly, if at all; delays of payments by six to twelve months were reported; some reported no payments for services rendered more than a year ago.
- Therapists who have not been reimbursed for several months or longer are leaving or considering leaving the system; many are going to school system for more consistent pay and less hassle.
- Decreased funding and smaller pool of providers result in waiting lists and service cuts.

Change in service model & procedures

- Change from the current successful model to a deficit-based medical model has more to do with saving money than serving children and families.
- Using only standardized assessment tools is not recommended.
- There were ethical and liability concerns expressed about therapists being asked to participate in a primary service provider model and provide cross-discipline therapies; for example, there are definite liabilities if a therapist is asked to provide a service he or she is not trained in, such as the use of feeding tubes.
- Concerns were expressed regarding use of paraprofessionals, assistants and/or clinical fellows to deliver therapy, which is illegal (since they are unlicensed) unless they are directly supervised by a licensed therapist, which would then add more cost to the service.

Regional challenges

- Services are more difficult to access in rural areas: there are small numbers of providers, and any who leave the system have high impact on the supply; there is difficulty with transportation; there is lack of access to alternative providers, such as hospitals.
- Services in natural environment are more difficult to provide due to therapist travel requirements over longer distances than in metro areas.

Summary of Common Themes Regarding the Revised Standards

As stated earlier in this report, there was, across almost all hearings, a consensus among attendees that the revised standards were unclear and confusing. Both parents and providers at several hearings said that they felt the broadly-stated standards were difficult to interpret vis-à-vis local practice implications. For example, how do the revised standards differ from the current standards and what does that mean to each local program? Many also expressed concern about being unable to get answers or clarification regarding both the nature of the potential changes and the timetable *as it might affect them personally*.

Unable to pinpoint how the standards would affect local practices, most of the attendees focused on areas that did *not* directly address specific sections and sub-sections of the program standards (a summary is reported on page 5). In some cases, attendees did comment on areas that related to some of the five sections of the revised standards, but only as a reaction to comments they heard (admittedly for the first time) from others at the podium that day.

In general, the written comments received by BCW (mail, e-mail, fax) reflected somewhat greater understanding of the revised standards. Among both hearing participants and written commentators, those who appeared to be more knowledgeable about the standards expressed concern that the revisions did not help solve the existing problem of inconsistency among districts but rather made consistent implementation of BCW practices almost impossible and staff training more difficult. Moreover, several commented that the standards did not address the key issues facing BCW with regard to sustainability and efficiency, and in some cases did not reflect the principles of Part C.

Listed below are some of the common themes heard from attendees at several hearings and reflected in written comments received at BCW with regard to the five sections of the revised standards. *It is important to note that:*

- (1) *The comments regarding specific sections are limited because of the factors stated above;*
- (2) *The range of these comments (and the fact that so many are expressed as questions) reflects the fact that there was a wide disparity in understanding of the actual standards and their implications.*

Comprehensive Child Find System

- Children 1st is slated to take a more active role in performing developmental screening; respondents were not sure how they are going to be able to handle this duty considering they have had a tremendous staff cut-back.
- Even with Children 1st as the single point of entry, BCW will not be able to meet the federally suggested benchmark of 2 percent of the birth-to-three populations if the turnover rate of BCW staff continues to increase.
- Children 1st and BCW need to be on the same page regarding consistency if Children 1st is to be the front door point of entry for all new Division of Public Health referrals

- Referral guidelines with regard to Children 1st are not clear; how will they be staffed and paid to handle referrals?
- Who will be responsible for monitoring the quality and efficiency of the intake activities done by public health staff?
- Using only standardized assessment tools for screening is not recommended; this is CMO-driven -- not in best interest of children.
- There is an emphasis on getting more children identified, yet there are fewer services and less funding available.

Evaluation and Assessment

- There is too much emphasis on standardized scoring versus “informed clinical” opinion when determining eligibility.
- Using a CMO as a case manager/service coordinator would be detrimental to the children and their families due to the fact that staff would probably never meet the family/child in person.
- Would the CMO staff attend the IFSP meeting, six month review and required annual review?
- Therapists acting as service coordinators could present problems; can therapists legally write IFSPs without specialized training?
- Problems already exist with timely communication between BCW and doctors’ offices; doctors do not have time to add new requirements/paperwork to their schedules; the end result will probably be delay of services past the 45 day requirement.

Individualized Family Service Plan (IFSP)

- There is confusion about the resource coordinator position vs. service coordinator position and their roles in IFSP and other areas; if the resource coordinator is housed at BCW it appears to transfer responsibility back to BCW without additional funding being provided.
- Waiting for physician’s input/signature on the IFSP will delay service; many doctors fail to complete the current paperwork obligations within specified time limits.
- What if the doctor disagrees with the IFSP, or the services they feel are necessary do not exist in the community or are not what the family wants?
- Concern was expressed that there are already problems with getting forms back from doctors’ offices in a timely manner and this standard adds another level of time-consuming paperwork for doctors.
- The end result of predicted delays due to paperwork will be delay of or reduction in needed services to children.
- Doctors may decide to drop Medicaid patients altogether if they have more administrative burdens placed on them.
- Have the physicians been asked if they have time to be more involved?
- Would the CMO staff attend the IFSP meeting, six month review and required annual review?

- Can therapists (acting as service coordinators) legally write IFSPs without specialized training?

Service Coordination

The Service Coordinator position in general

- Service coordinators are the core of the BCW program.
- The service coordinator is a highly experienced and trained position; how could this be replicated by someone who is trained for and doing another job?
- If independent service coordinators are eliminated, there will be no neutral party to defend/obtain needed services for children.
- Service coordinators provide objectivity as well as anonymity.
- Service coordinators know the community and are therefore able to connect families to resources even outside of their medical needs.
- Why does the “resource coordinator” have to be a public employee?

Therapists acting as Service Coordinators

- Therapists are not trained to be service coordinators.
- Who will be responsible for training therapists or CMO staff to be service coordinators. and for supervising them? What about training updates, job descriptions, reviews?
- How will the cost of service coordination be accounted for if a therapist or CMO handles service coordination?
- A conflict of interest possible if therapists also function as service coordinators.
- Could therapists legally write IFSPs without specialized training?
- Therapists are too busy to add service coordination to their duties; it would overwhelm them.
- Therapists will not take on these extra duties if the pay stays the same.
- All important tasks provided by service coordinators could not be fully shouldered by therapists.
- What recourse does a parent have if there are problems with the therapist and that person is acting as the service coordinator?
- Therapists will not have the knowledge and/or resources to assist families dealing with grief, depression, marital stress, problems with siblings, etc.
- Will therapists have to cancel appointments to take children/families to transitional meetings?

CMOs acting as Service Coordinators

- The service coordinator job is extensive and requires local knowledge and face-to-face contact with the families; CMO staff, acting by telephone from a distance, could not do the job well.
- Concern was expressed about CMO staff being trained per federal regulations.

- There was concern about CMO staff being both service coordinator and gatekeeper for funds, an apparent conflict of interest.
- Using a CMO as a case manager/service coordinator would be detrimental to the children and their families due to the fact that staff would probably never meet the family/child in person

Service Delivery

Provider shortages

- Provider shortages are beginning to adversely affect the program; many providers have left the program due to non- or late-payment issues and documentation requirements from CMOs and Medicaid.
- There is concern that BCW can't compete with schools, hospitals and other entities that pay providers well and consistently.
- Lack of hospital-based "other" providers was cited.
- It was suggested that provider shortages be shown geographically on the BCW website.
- Services are more difficult to access in rural areas: there are small numbers of providers, and any who leave the system have high impact on the supply; there is difficulty with transportation; there is lack of access to alternative providers, such as hospitals

Service delivery model changes and general comments

- Changing from the current successful model to a deficit-based medical model has more to do with saving money than serving children and families.
- Ethical and liability concerns of therapists being asked to participate in a primary service provider model and provide cross-discipline therapies; for example, there are definite liabilities if a therapist is asked to provide a service he or she is not trained in, such as the use of feeding tubes.
- Concerns were expressed regarding the use of paraprofessionals, assistants and/or clinical fellows to deliver therapy, which is illegal (since they are unlicensed) unless they are directly supervised by a licensed therapist; this would then add more cost to the service since there would be two people to be paid, and it would be unlikely CMOs or Medicaid would accept this.
- It was suggested that, to enhance efficiency of service delivery, BCW should put blank forms in .pdf format on the website so that providers can e-mail information to service coordinators (versus using snail mail).
- Services in natural environment are more difficult to provide in rural areas due to therapist travel requirements over longer distances than in metro areas.

Implications of managed care organizations' practices

- Managed care organizations have onerous paperwork requirements, requiring repeated re-submission of paperwork due to submissions lost at the CMOs and minor variances in filling out forms.

- Managed care organizations reimburse therapists extremely slowly or not at all; delays of payments by six to twelve months were reported; some reported no payments for services rendered over a year ago.
- Therapists who have not been reimbursed by CMOs for several months or longer are leaving or considering leaving the system; many are going to school system for more consistent pay and less hassle.
- Decreased funding and smaller pool of providers result in waiting lists and service cuts.