

#### Early Intervention Because **Babies Can't Wait**

# Facts for Physicians & Healthcare Providers

Source: Babies Can't Wait Early Intervention Program 2000-2001 Annual Report, Georgia Department of Human Resources.

## message from us...

The Babies Can't Wait (BCW) program continues to be committed to providing family-centered services that are consistent with evidence-based practices within the field of early intervention. The state and district offices are cooperatively engaged in many initiatives and priorities that will continue to promote better outcomes for young children with special needs and their families. It is an exciting and busy time to be involved in early intervention in Georgia!

One current focus within BCW is the development and provision of training in a variety of modalities throughout the state. Training is being designed to support continued improvement of the BCW system through service delivery that ensures full implementation of the natural environments mandate in the Individuals with Disabilities Education Act (IDEA). In addition to providing supports where the child spends time (e.g., home, child care, McDonald's, grandma's house), each child's learning is integrated into the daily routines and activities in which he or she is involved. Families receive support from therapists, educators, and/or other team members to increase learning opportunities in meaningful contexts (e.g., favorite games, mealtimes, bath time, play, car travel, shopping), as identified by the family. While each child will have access to a multidisciplinary team, families will be supported primarily by a single provider, who draws on the expertise and knowledge of other team members. Coaching with family members and across other team members is integral to this approach and will likely decrease the occurrence of fragmented services that are too often encountered. Ultimately, the true intent of early intervention—to enhance the capacity of family members to meet the needs of their child and support child learning—will be realized through such changes In order to ensure the effective provision of these evidence-based practices, ongoing collaboration with therapy associations, families, referral sources, higher education faculty, potential funding sources, and district and local providers and stakeholders will be ongoing.

Another priority in Georgia and throughout the United States is focused on ensuring that all potentially eligible children and their families have access to early intervention services. As of December 1, 2003, 4,840 children were enrolled in BCW statewide. Based upon 2000 United States Census data and national goals, 7,165 children should be enrolled in BCW on any given date. This number represents approximately 2% of the total population of children birth to three years of age. In the past year, approximately 21% of state referrals came from Children 1st, the Division of Public Health system single point of entry, while 20% of referrals were received from physicians. The remaining referrals came from other community sources, including families, child care providers, health departments, early intervention providers, and other community partners. Currently each district BCW program is implementing improvement plans designed to increase the early identification of young children. Training and public awareness activities vary widely from district to district, and efficacy data are gathered to evaluate impact of activities.

We appreciate your collaboration in these efforts, and we value your contributions as a community partner. For further information, please contact either the State BCW Office (404-657-2726 or toll free 888-651-8224) or the North GA Health District 1-2 BCW Office (706-272-2219 or toll free 888-276-1558).

Thank you for your cooperation and support.

Stephanie Moss, Georgia Part C Coordinator Debbie Coleman, BCW Coordinator for North Georgia Health District 1-2

## Babies Can't Wait What is it?

comprehensive, familycentered, coordinated, multidisciplinary system that provides early intervention services to infants and toddlers with disabilities or developmental delays and their families. The BCW

system is implemented under Part C of the Individuals with Disabilities **Education Act** (IDEA). Georgia has par-

ticipated in Part C of IDEA since 1987. BCW is administered by the Georgia Department of Human Resources, Division of Public Health, Family Health Branch. For families of eligible infants and toddlers, BCW provides a window of opportunity for their children to

Babies Can't Wait (BCW) is a grow, learn and develop to their fullest potential. For professionals, BCW is the chance to give infants and toddlers, whose brains are growing quickly, the opportunity to gain skills, and the chance to teach families to help their children learn

> these skills. It is the collaboration between families and professionals that makes BCW so unique.

For more information, visit the BCW web site at http:// health.state.ga.us/programs/ bcw/.

You can contact the State Babies Can't Wait office at 404-657-2726 or toll free at 888-651-8224.

## Who is eligible for BCW?

Part C of IDEA is designed for children from birth to age 3 years who need early intervention services and supports because they are experiencing a significant delay in one or more of the following areas of development: physical, cognitive, communication, social/ emotional, or adaptive; or because they have a diagnosed mental or physical condition that has a high probability of resulting in a significant delay.

Continued on the back





270.1

330.1

270.2

Phenylketonuria (PKU)

Tyrosinemia

Tay-Sachs (GM-2 gangliosidosis)

# Established-Risk Conditions

Children under 3 years of age with the following confirmed diagnoses are automatically eligible for Babies Can't Wait.

#### INTRAUTERINE INFECTIONS MITOCHONDRIAL DISEASES Cytomegalovirus (CMV) Herpes Simplex, congenital 771.2 Leigh's Disease (sub acute necrotizing encephalopathy) Other Specified Disorders of Metabolism 771.0 Rubella, congenital 358.9 090.9 Syphilis, congenital Oxidative Phosphoryiation Disorders Toxoplasmosis Pyruvate Carboxylase Deficiency 771.2 Pyruvate Dehydrogenase Deficiency CENTRAL NERVOUS SYSTEM ANOMALIES Aicardi Syndrome (reduction deformities of brain) NEUROMUSCULAR DISORDER 742.2 Alternating Hemiplegia of Childhood 740. Anencephaly 342.8 742.9 Colpocephaly 343.9 Cerebral Palsy (CP) 742.3 Dandy Walker Syndrome (congenital hydrocephalus) with 359.0 Muscular Dystrophy associated anomalies 359.0 Myotubular Myophathy (MTM) 742.0 Encephalocele 359.0 Nemaline Myopahty (NM) Spinal Muscle Atrophy (Werdnig-Hoffman Disease) 742.2 Holoprosencephaly 335.0 742.9 Hydranencephaly 331.3 Hydrocephalus (acquired; communicating) HYPOXIC ISCHEMIC ENCEPHALOPATHY 331.4 Hydrocephalus (acquired; obstructive or non communicating) WITH MRI OR CT CHANGES 771.2 Hydrocephalus (associated with congenital toxplasmosis) 331.9 Cortical Atrophy (Cerebral cortical atrophy) Hydrocephalus (associated with spina bifida) 741.0 Intraventricular Hemorrhage (IVH) Grade III or IV 772.1 742.9 Isotretinoin (Accutane) Embryopahty (IE) 434.9 Periventricular Leukomalacia (PVL) 330.0 Leukodystrophy, Metachromatic (MLD) 742.2 Lissencephaly (Argyria-Pachygyria, Macrogryria) SIGNIFICANT CENTRAL NERVOUS SYSTEM INJURY 742.1 Microcephaly with NEUROLOGICAL IMPAIRMENT (Postnatal Events) 741.9 Myelomeningocele 742.9 Polymicrogyria 348.3 Encephalophathy 742.4 959.01 Head Injury (Significant) Porencephaly 742.9 Schinzel-Giedion Syndrome (SGS) 320 Meningitis (Severe neurological insult) 742.4 Schizencephaly **AUTISTIC SPECTRUM DISORDERS** MAJOR CHROMOSOMAL ABNORMALITIES 299.0 758.81 49XXXXY 299. Pervasive Development Disorder (PDD) 758.3 Chromosome 3 p Deletion 330.8 Rett Syndrome 758.3 Chromosome 4 p (Wolf-Hirschhorn Syndrome, WHS) 758.3 Chromosome 13Q Syndrome (autosomal deletion syndrome) OTHER CONDITIONS AND MAJOR SYNDROMES 758.3 Chromosome 18q (deletion) Angelman Syndrome 759.89 758.3 Chromosome 22 (deletion) 755.55 Apert Syndrome (Acrocephalosyndactyly, Type I) 758.3 Cri-du-Chat Syndrome (chromosome 5p syndrome) Bannayan-Riley-Ruvalcaba Syndrome (BRRS) 756.5 Down Syndrome (DS, Trisomy 21) 758.0 759.89 **CHARGE** Association 758 Pallister-Killian Syndrome 759.89 Cornelia de Lange Syndrome (Brachmann-de Lange Syndrome) 758 Trisomy 7 760.71 Fetal Alcohol Syndrome (FAS) (Definite) Trisomy 13 (Patau Syndrome) 758.1 759.83 Fragile X Syndrome 758.2 Trisomy 18 (Edwards Syndrome) Klippel-Feil Syndrome 756.16 Trisomy 9 758.5 270.8 Lowe Syndrome (Cerebro Oculorenal Dystrophy or 758.5 Trisomy 15 Oculocerebrorenal Syndrome) 758.5 Trisomy 16 759.89 Noonan Syndrome 758.5 Trisomy 19 Prader-Willi Syndrome 759.8 756.4 Rhizomelic Chondrodysplasia Punctate, Type 1 **METABOLIC DISEASE (Autosomal Recessive Disorders)** 759.89 Rubinstein-Taybi Syndrome Carbohydrate Deficiency Glycoprotein Syndomre (CDGS), Type 1 345. Seizure Disorder (Epilepsy, excluding febrile seizure) Galactosemia, congenital Severe Combined Immunodeficiency Syndrome (SCID) 271.1 279.2 270.4 Homocystinuria (HCU) 389.9 Severe Hearing Impairment, Known (Bilateral) 243. Hypothyroidism (CH), congenital 369.9 Severe Visual Impairment, Known 270.3 Maple Syrup Urine Disease (MSUD) 759.8 Shprintzen-Goldberg Syndrome Mucopolysaccharidosis 759.89 Smith-Lemil-Opitz Syndrome 277.5 Hunter Syndrome 758.3 Smith-Magenis Syndrome Hurler Syndrome 759.6 Sturge-Weber Syndrome Sanfilippo Syndrome 759.5 Tuberous Sclerosis (TS)

759.89

Williams Syndrome (Idiopathic infantile hypocalcaemia syndrome)

# Resources Available

All formal and informal resources, determined to be necessary for the child and family through the evaluation/assessment process, are organized in an Individualized Family Service Plan (IFSP). Parents and service providers are partners in developing this plan.

The IFSP is based on each family's resources, priorities and concerns, and includes only the early intervention activities and supports that the family chooses and which are recommended as necessary to promote progress toward outcomes on the IFSP.

Part C of IDEA requires participating state programs to make the following early intervention services and supports available as appropriate for each individual child and family (and according to the IFSP):

- Assistive technology
- Audiology
- Family training, counseling and home visits
- Health services (needed to enable a child to benefit from other early intervention activities)
- Medical services (certain diagnostic and evaluation services)
- Nursing (needed to enable a child to benefit from other early intervention activities)
- Nutrition
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination
- Social work services
- Special instruction
- Speech language therapy
- Transportation services
- Vision services

Each family is assigned a service coordinator whose job is to help the family coordinate the early intervention process, to access services and resources and to work with the family to meet their unique needs. The service coordinator is a critical link to the community and to information and resources.

One intention of the federal legislation is to support families within the context of their lives and their communities. Services received through BCW are provided in the child and family's "natural environment," which means places and situations where children without disabilities or delays live, play and grow. These include the child's home, child care, community play groups,

## How does a family find us?

Anyone, including a parent, who is concerned about an infant's or toddler's development may make a referral to BCW. Participation in BCW is voluntary.

Referrals may be made directly to the local BCW office at the North Georgia Health District 1-2, which serves Cherokee, Pickens, Gilmer, Fannin, Murray and Whitfield counties.

Referral for residents in these counties may be made by calling BCW Dalton office at 706-272-2219 or 1-888-276-1558.

There is a local BCW office in each of Georgia's 19 public health districts.
Referrals can also be made to the State BCW Central Directory at 800-229-2038 or 770-451-5484 in Atlanta, or to the local health district's Children 1st Coordinator.

The Directory is operated by Parent to Parent of Georgia, a statewide parent-run organization. In addition to obtaining information about BCW, parents can also be matched with supporting parents whose children have similar disabilities. Visit the Parent to Parent web site at: <a href="https://www.parenttoparentofga.org">www.parenttoparentofga.org</a>.

### Transition

Some children will leave BCW before or at age 3 years and participate in programs and activities with or without specialized assistance and services.

All children leaving BCW must have a plan for their "transition" from early

intervention. The service coordinator will assist the family and serve as a link between BCW and whatever is to follow in order to ensure a smooth, seamless transition to other services or systems appropriate for the child and his/her family. This process begins



at least six months prior to a child's third birthday and enables the family to become familiar with their public preschool special education personnel, private preschool opportunities, Head Start and other options in their community.

As families prepare to leave BCW, their service coordinators make sure appropriate community referrals are made to programs within the health department and other agencies to assure health and other needs are addressed.

## Who is eligible?

#### Continued from front

To be eligible for BCW, children must meet one of the specific eligibility criteria defined below (NOTE: There are no income eligibility requirements for BCW):

#### **Established condition**

A child with a diagnosed mental or physical

condition that is known to result in a developmental delay, even when no delay exists at the time of the referral; or

#### Developmental delay

A child with a significant developmental delay that is confirmed by a qualified multidisciplinary team.

### Physician Policies

For more information about the following policies, visit the American Academy of Pediatrics web site at: <a href="https://www.aap.org/policy">www.aap.org/policy</a>.

#### Policies include:

- The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP) (RE9823)
- Role of the Pediatrician in Family-Centered Early Intervention Services (RE0037)
- The Role of the Pediatrician in Prescribing Therapy Services for Children With Motor Disabilities (RE9629)

Also, visit <u>www.aap.org/research/</u> <u>periodicsurvey/ps53exs.htm</u>

## Facts for Physicians

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