

The Parent Coalition of Whatcom County

July 2002

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Issue No. 7-02



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AUGUST 2002

1 Thursday - Bellingham

People First of Whatcom County picnic & concert at Elizabeth Park. Meet at 5:30 by the bandstand. Concert 6-8 pm. *Bring your own food, drinks, blankets and pads to sit on.* 360-715-0170 ext. 3.

2 Friday - Bellingham

Parent to Parent Family Swim Social. 6:30-7:30 pm. Arne Hanna Aquatic Center. *Bring the whole family!*

5 Monday - Bellingham

The Arc of Whatcom County Board of Directors meeting. 4-6 pm. 1111 Cornwall Ave., #204. 360-715-0170.

12 Monday

No Whatcom County Developmental Disabilities Advisory Board meeting.

19 Monday - Bellingham

SPIN Summer Picnic and Dance. Picnic 6 pm, dance 7-9 pm. Max Higbee Center, 315 Halleck St. *Reservations needed for picnic, call 676-6985.*

19 Monday - Bellingham

Parent to Parent support meeting. 7 pm. Whatcom Center for Early Learning, 2001 H Street. 360-255-6402.

24 Saturday - Bellingham

Parent to Parent Sibshop, ages 8-13 years. 10 am-2 pm. Bloedel Donovan, Small Pavilion. 360-255-6402.

SEPTEMBER 2002

4 Wednesday - Bellingham

Whatcom County Developmental Disabilities Advisory Board Planning Committee. 4:30 - 6 pm. 360-676-6829.

9 Monday - Bellingham

The Arc of Whatcom County Board of Directors meeting. 4 - 6 pm. 1111 Cornwall Ave., #204. 360-715-0170.

9 Monday - Bellingham

Whatcom County DD Advisory Board meeting. 4:30 - 6 pm. 1000 N. Forest St. 360-676-6829.

24 Tuesday - Bellingham

Whatcom County DD Advisory Board Planning Committee. 5 - 7 pm. 360-676-6829.

26 Thursday - Lynden

People First of Lynden. 8800 Bender Road (Sonlight Church). 5-6:30 pm. 360-715-0170 ext. 3 for info.

27 Friday - Bellingham

People First of Bellingham. Max Higbee Center, 315 Halleck. 7-8:30 pm. 360-715-0170.



Division of Developmental Disabilities Program Descriptions

Case and Resource Management

A case manager is assigned to assess the needs of clients and families and link and connect these needs to available services. Case managers coordinate planning and development of resources, authorize payment, monitor and review service delivery, provide information about available services, refer persons to other sources of support, and do crisis intervention.

Long-Term Care Services

Long-term care services may be provided either in a residential facility or in a person's own/family home. These individuals may receive other supports from a variety of sources to enhance their functional and adaptive skills, including medical, dental, professional therapies, transportation, and medically intensive services.

Residential Services

Facility Based Programs – In these residential programs the provider owns or leases the facility and room and board expenses are included in the rate paid by the division. Residents participate towards the cost of care. State employees provide services in 5 state operated residential facilities (RHCs). To provide services in a variety of smaller facilities located in community settings the division contracts with organizations, or coordinates with other DSHS divisions. All facility based programs offer 24-hour supervision.

Non-Facility Based Programs – These programs are provided to persons who live in their own homes in the community. Except for the SOLA program, the division contracts for these services with organizations or individuals who provide services for a few hours per month, up to 24 hours per day. Clients pay for their own rent, food, and other personal expenses. The division pays for staff to provide support and training in the client's home.

In-Home Services

Medicaid Personal Care (MPC) – This federally matched state-plan Medicaid service provides personal care assistance for Medicaid eligible persons assessed as needing assistance with at least one direct personal care task as a result of the person's disability. This service is provided in the person's own home, adult family home, or adult residential center as a Medicaid "entitlement".

Family Support – Provides families with the supports necessary to keep individuals at home with parents or relatives. Includes respite care, attendant care, transportation, specialized aides and therapies.

Attendant Care – Temporary or ongoing in-home attendant or personal care services are available to persons who do not qualify under the MPC or Family Support programs.

(continued on page 4)

The Arc of Whatcom County serves Whatcom, Skagit and Island Counties. Our mission is to improve the quality of life, increase the independence, and assure the full inclusion in the community of any person with a developmental disability.

**Department of Social and Health Services
Division of Developmental Disabilities (DDD)
Supplemental Security Income/
State Supplementary Payments (SSP)**

Major Policy Change: Converting Services to Cash

Major policy changes as directed through the 2002 legislature are causing concern and fear among families and service providers. The 2002 supplemental budget directs DDD to use a portion of existing service dollars from family support and high school transition, as well as a portion of new dollars from The Arc lawsuit settlement (see following article) in the form of State Supplementary Payments (SSP). The State has agreed to limit SSP payments to persons who qualify for Supplemental Security Income (SSI) payments. The Social Security Administration has recently (July 1, 2002) granted approval to the Division's SSP plan.

Implementation details are still in the works. Services for July and August will be authorized as usual, with cash payments to begin in September.

As of June 25, 2002, the tightly limited eligibility criteria for SSP is:

- 1) Be clients of DDD and
- 2) Be eligible to receive a SSI payment and
- 3) Must have received a state-only funded DDD service (Residential, Voluntary Placement, Family Support or High School Transition) in the prior year and still be in need of this service.

For more information: Jane Boone, DDD: 360-902-8446



Lawsuit: Many individuals with developmental disabilities have been on waiting lists for Medicaid services. After over two years since filing, the lawsuit settled on April 4, 2002. The court is making its preliminary decision and the clients of the DSHS Division of Developmental Disabilities (DDD) will be asked for input.

Benefits of the settlement: More Medicaid services will be provided to individuals with developmental disabilities. Approximately \$362 million will be provided under the agreement to DDD clients through FY (Fiscal Year) 2003-2007; \$107.1 million each year thereafter.

So far, the new money is planned to be distributed over the following areas: Community Residential Services, Family Support Funding, Day Program Funding, High School Transition Funding. Some of the remaining funds will also be used for quality assurance, staffing, and public safety.

Details: Precise services provided to individual class members will remain individually determined according to service plans developed between individuals and DDD staff. Some broad provisions are that funds will be used to serve Home & Community Based Waiver (HCBS- also known as CAP waiver) clients and those clients not already on the HCBS waiver:

- In year 2003, 75% of the funds will serve existing HCBS clients; 25% will serve those not on the HCBS waiver.
- In year 2004, 50% of the funds will serve existing HCBS clients; 50% will serve those not on the HCBS waiver.
- In year 2005, 25% of the funds will serve existing HCBS clients; 75% will serve those not on the HCBS waiver.

Individuals should contact their case manager at DDD for more information on HCBS/CAP waivers.

**In Region III, Whatcom/Skagit/Island/San Juan Counties:
1-800-788-2053**

**Individuals with
Disabilities Education Act (IDEA)
A national assessment**

In summary: Graduation rates for students with disabilities has gone up and the drop-out rate has decreased. The participation rate for this assessment has also gone up in half of the states. Graduation requirements in schools vary on the basis of individuals and more attention is being given to develop various life-long skills. Parents are encouraged to assist their children in making transition from school to adult life.

Over fifty percent of the students under IDEA that have emotional and behavioral disorders are dropping out of school -- this means that they lack social skills and educational knowledge needed to be successful in the community. To help solve this problem, early positive behavioral support is needed. Good health, family support, and education can improve the future of your children.

Although the number of students (ages 6-21) under IDEA Part B has increased 2.6 percent from the 1998 - 1999 year, there is a *shortage in the number of personnel* serving students with disabilities. There aren't enough suitable candidates, which means that children will get less attention concerning their individual needs.

Office of Special Education (OSEP) is trying to monitor and gather information from previous assessments to improve the current program. For more information about Special Education services in your area:

Whatcom County:

Special Ed Director: Dr. Judy Barton
Lynden School District
(360) 354-4443

Special Ed Director: Pat Bieber
Mt. Baker School District
(360) 383-2000

Special Ed Director: Adam Craig & Toni Dahlquist
Nooksack Valley School District
(360) 988-4754

Special Ed Director: Sue Thomas
Bellingham School District
(360) 676-6400

Special Ed Director: Jan Polen
Blaine School District
(360) 332-5213

Special Ed Director: Michael Berres
Ferndale School District
(360) 383-9200

Skagit/Island/San Juan Counties:

Carol Taylor
Northwest ESD 189 (www.esd189.org)
205 Stewart Rd.
Mount Vernon, WA 98273
(360) 416-3412; email: ctaylor@esd189.org

Inside the world of autism

Excerpts from "The Secrets of Autism," the May 6, 2002 cover story in *Time* magazine, pages 46-56, written by J. Madeline Nash, with reporting by Amy Lennard Goehner and Amy Bonesteel.



What is autism? It is a brain disorder which occurs in the early years of childhood. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence. However, components of autism tend to run in families. Scientists currently believe that the roots of autism lie in genetics, which is one of the

reasons there isn't a cure for this life-long disorder yet. The topic of genetics is fairly new and has more recently attracted the attention of top researchers and scientists.

Autism spectrum disorders used to be rare, but now studies show that 1 out of 150 children (under the age of 10) can be affected by the disorders. According to the Autism Society of America, more than a million people in the U.S. (children and adults) suffer from one of the autism spectrum disorders - also known as pervasive developmental disorders or PDDs.

More psychologists, psychiatrists, biologists, etc. are developing theories on the possible causes of autism spectrum disorders. Environmental, food, behavioral, and hereditary factors are being considered.

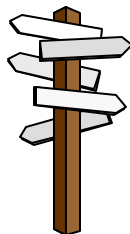
High-tech equipment is being used to compare the brains of children with autism and children without autism. The human brain is one of the most complicated parts of the body. Examining the brain at the molecular level suggests that there could be as many as 20 genes that contribute to the autism spectrum disorders. Some of the problems that people with autism experience include

- Sensory disturbances
- Food allergies
- Gastrointestinal problems
- Obsessive compulsiveness
- Attention deficit hyperactivity disorder

The brain of a person with autism fails to fully develop the early stages of life. Children between 3 to 5 years old start expanding their knowledge by trying different things, such as imitating their parents. Children with autism spectrum disorders assume that everyone else's mind is like their own, and that others think and feel the same way they do. These children cannot read or interpret other people's feelings the way most people do, from things like body language and small facial expressions. Most people with autism do have the ability to distinguish close relatives and friends from strangers.

The brain of a child with autism is normal in size at birth, but by the time the child is 2 to 3 years old the brain size is larger than normal. Also, the

brain hasn't grown proportionally in all areas. Reasons for this growth are still not known, nor is it known or understood how to alter or change it.



Signs of autism

- No pointing by age 1
- No babbling by age 1; no single words by the 16th month
- Any loss of language skills at any time
- No pretend playing
- Little interest in making friends
- Short attention span
- No response when called by name; lack of interest in others
- Little or no eye contact
- Repetitive body movements (hand flipping, rocking)
- Intense tantrums
- Focused/concentrated on a single object
- Unusually strong resistance to changes in routines
- Oversensitivity to certain sounds, textures or smells



Things that help

- Speech therapy can help a child with autism communicate and speak better
- Occupational therapy can help sensory integration and motor skills
- Behavioral therapy can help improve behavior
- Educational therapy can help expand knowledge in a structured approach
- Medication
- Special diets may help some children (omitting some foods from the diet, for example)

Early recognition and treatment of any brain disorder is always important. Free evaluation and early intervention services for children are provided in our area:

For information on Early Intervention services, contact:
Children with Special Health Care Needs
Maureen Godwin - Family Resource Coordinator
360-738-2522

More information on autism, contact:
Karlene Carlson
FACES (Families For Autistic Children's Education & Support) 360-738-5298

A directory of professionals working with autism and related disorders in our area is available from:
Karen Roe, 206-782-2232
fishmama@qwest.net

DDD Program Descriptions

Employment and Day Programs

Approximately 40% of the adults enrolled by the division are involved in an employment or day program. Eighty-four percent (84%) of children on the caseload under the age of 3 receive their early intervention services through the division's contracts with counties. The counties select and contract with local service providers.

Employment Services

These services provide ongoing support services and training for eligible persons with paid jobs in a variety of settings and worksites, including individual or group options in the community and specialized industry settings.

Community Access

These programs emphasize the development of social, communication, and leisure skills for individuals whose age or disability limits their participation in employment. Persons gain access to community activities through special assistance, advocacy, and education.

Child Development Services

These services are enhanced and monitored through the Infant Toddler Early Intervention Program (ITEIP). They include therapy, education, family counseling, and training, and are provided to children until age three. When a child turns three, he or she becomes eligible for services through public schools or other community programs.

Person-to-Person

As an extension of Community Access, services and supports are offered to assist people with disabilities, their families, friends and allies to: (1) articulate a personal vision for a desired life in the community; and (2) locate and connect people to sources of personal support in the community that enhance the vision for a desired life. Services and supports may include, but are not limited to: person centered planning, skill instruction, information, referral, physical support and one-to-one relationship building.

Individual and Family Assistance

Time limited projects to meet one or more of the following outcomes:

- (1) to provide supports to additional families and persons with developmental disabilities in need of services and supports within existing resources;
- (2) to provide individuals and families receiving services more control and flexibility with the use of the resources;
- (3) to assist the individual and family in connecting to and using natural and informal commu-

nity supports.

Special Programs

Infant Toddler Early Intervention Program (ITEIP)

The ITEIP enhances and coordinates existing early intervention services and assures that federal service standards are followed. These services include family resources coordination, therapies, and family training and counseling for infant and toddlers, birth to three, with developmental delays or disabilities.

Community Protection Program

This program provides intensive 24-hour supervision for individuals who have been identified as being a danger to their community due to the crimes they have committed. The program is an opportunity for participants to live successfully in the community and continue to remain out of prison or other justice system settings.

Developmental Disabilities/ Mental Health Collaborative Plan

This plan includes a variety of strategies and partnerships with mental health staff and community-based organizations to divert individuals with developmental disabilities from psychiatric hospitalization through crisis intervention, prevention, behavioral support and technical assistance, residential outplacement capacity and medication evaluation and monitoring.

Source: DSHS Division of Developmental Disabilities - Program Summary, Feb. 2002.

Note: This is a summary of current services. See page 2 for related stories on how services will be Prevention

Fetal Alcohol Syndrome (FAS) rates unchanged

Some developmental disabilities can be prevented. Drinking during a pregnancy can cause a child to have Fetal Alcohol Syndrome (FAS). A child with FAS can have long-term mental, developmental and behavioral problems.

The Center for Disease Control and Prevention (CDC) reports (in its Morbidity and Mortality Weekly Report, May 24, 2002) that the number of FAS cases has not declined since 1995, even with more public educational programs about Fetal Alcohol Syndrome.

Fetal Alcohol Syndrome Surveillance Network (FASSNet) is a program that examines and tracks the FAS cases. The FAS rate is highest among African-Americans, American Indian and Alaska Natives.

The solution to Fetal Alcohol Syndrome is clear: no drinking AT ALL during pregnancy. If a woman is drinking in the earliest months of a pregnancy, before it is confirmed, the developing child has been exposed to alcohol and is at risk for FAS.

Washington State Special Ed Training

for educators and families

Free one-week special education training courses being offered this summer by WSSETA. Courses offered in Mt. Vernon. Courses emphasize rights, responsibilities, and building lasting relationships while working as a team.

For more information, contact:
Carol Towne
(360) 416-3415
email: ctowne@est189.org
http://www.wssec.org

"Special Ed Boot Camp" for special ed staff and families

- August 19-23 in Mt. Vernon/La Conner.
- Registration deadline is August 2.
- Five scholarships available

For more information, contact:
Shirley Jeffrey
(253) 765-7074
email: sjeffrey@wa.nea.org
http://www.wa.nea.org

Parent to Parent of Whatcom County 715-0170 or 255-6402

We apologize for any inconvenience or confusion caused by our recent telephone technical difficulties. Thank you for your patience and please call us!

**Kerry Hodgkinson
Parent to Parent Coordinator**

Sibling Support [www.thearc.org/ siblingsupport](http://www.thearc.org/siblingsupport)



A national program which advocates brothers and sisters of people with special health and developmental needs.

Family Village Website



<http://www.familyvillage.wisc.edu>
Family Village tries to bring together valuable information to parents and families of those individuals who have various disabilities.

Center for Children with Special Needs

<http://www.cshcn.org>

Around 18 million children in United States have special health care needs. The Center for Children with Special Needs tries to help these children by providing special health care and information for the children and their families. They offer programs such as:

- Health Consultation Program
- Families-As-Teachers
- Parent Support Program
- Family Consultant Program



National Fathers Network

<http://www.fathersnetwork.org>

WA Fathers Network: <http://www.fathersnetwork.org/707.html>

Supports fathers and families of children with chronic illnesses and developmental disabilities. The information provided on the website is designed to promote the spirit of all family members. Contact 715-0170 if interested in joining a local Fathers Network.

IEP Individualized Education Plan

What is an Individualized Education Plan?

An individualized education plan (IEP), is both the written document listing the essential components of a student's appropriate educational program and the collaborative process between the parents and the school by which the plan is designed. IDEA (Individuals with Disabilities Education Act) defines an IEP as "a written statement for a child with a disability that is developed and implemented in accordance with IDEA."

IEP requirements:

- (1) when an IEP meeting must be initiated and how it must be conducted;
- (2) who may or must attend IEP meetings;
- (3) rights of parents to participate in the IEP process;
- (4) items that the IEP must address (the contents of the IEP document)

Contact 715-0170 for a Parent Advocate to help with your IEP!



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The Arc of Whatcom County Board of Directors

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Jan Carlson, Michele Hill, Kristina Hoffman, Connie Knau,
and Susan Larson.

There are currently three vacancies on the Board.

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Susan Jewell

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9 am - Noon, Monday-Friday



THE ARC OF WHATCOM COUNTY

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Bellingham, WA 98225



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CHOICE & SELF-DETERMINATION

People with developmental disabilities and their families want services and supports delivered by a system that allows us choice and control over our own lives. (Jennifer Wilke's column will return in August)



DSHS Moves To Improve Accountability In The Changing World Of Developmental Disabilities

OLYMPIA - The Washington Department of Social and Health Services (DSHS), the state agency that supports 33,000 people with developmental disabilities, reports that it is undergoing comprehensive change to improve the services and the data used to manage its \$595 million annual operation.

The Department of Social and Health Services' Division of Developmental Disabilities is making these changes based on the findings of Sterling Associates, an Olympia-based management consulting firm.

"As Sterling Associates points out in a report released May 24, 2002, our Division of Developmental Disabilities (DDD) is undergoing a sea change - trying to support our family members with disabilities in our communities and provide a large array of choices to them as their life spans grow dramatically - at a time when budgets aren't keeping pace with caseload growth," said DSHS Secretary Dennis Braddock.

"The division has begun work to change those systems. We've started to make changes, and the Sterling report will provide a roadmap to a comprehensive change in the way we do business," Braddock added. He noted DSHS hired Sterling to critically analyze the division - and suggest where improvements could be made.

The department already has hired Bruce Mrkvicka, a finance expert, to help the division identify and standardize the key data elements it needs to provide credible information. Mrkvicka is leading an effort to utilize an effective data

system that will provide case managers the crucial data they need from other DSHS administrations and programs to serve their clients with developmental disabilities.

As recommended by Sterling, the division also is preparing to hire an assistant director who will focus on improving the operations of the division in response to the Sterling findings and questions raised by the Joint Legislative Audit and Review Committee. The Sterling report also recommends the hiring of a communications expert to ensure the flow of pertinent and accurate information. They will be supported by a new Compliance Team whose job will be to:

- Write standardized rules for all regions of the state
- Identify appropriate and effective ways to process data
- Train case managers and other employees

Braddock said he is reviewing major reorganization possibilities for the division in response to the report. (See <http://www.wa.gov/dshs/mediareleases/pdf/DDDFinalReport.pdf> or <http://www.wa.gov/dshs/cwofdd/index.html>)

"It is imperative that we establish a cost-effective, transparent continuum of care for those needing services," Braddock said. "The world of clients with developmental disabilities is changing radically, and our management structure must be organized to accommodate this change effectively. We also are taking to heart Sterling's recommendation to communicate in a coordinated way with clients, employees, stakeholders, decision makers and elected officials about our clients, our challenges and our achievements," Braddock said.