

**KEY**

**CAMPAIGN,**

**2003**

SFIN

FILE

And **WHY** are we here in Juneau?

Did you know?

- Today, over 1,200 individuals with developmental disabilities are on the State's Wait List for critical community services.
- The average wait is 3-5 years - often a direct cause of broken families and out-of-home placements.
- There is a huge cost savings when a family's needs are met when they first arise.
- The average costs for adults with disabilities to live in the community are half of what it costs to live in a nursing home or institution.

All of the above are facts based on research and data. Community supports make sense, both fiscally and programmatically, and that's why we're here in Juneau.

We believe that children should remain at home with their parents, with adequate supports to assist mom and dad with the special challenges and stresses that can be a part of disabilities.

We believe that adults with disabilities have a right to live in neighborhoods of choice; to have meaningful jobs; to have opportunities to contribute back to their community; to live a life of dignity and value.

So we ask your help. We need our Governor and Legislature to be certain that the Family of Alaska includes people with disabilities. We need modest assistance with a progressive, systematic drive and commitment from both, to end the Wait List **NOW!** Please join us as we march, rally, and advocate. Tell our elected officials that you believe in the dream of this Key Campaign - that **COMMUNITY** is for everyone and that the time to end the waiting is now.

Thank you on behalf of our families, our children, adolescents and adults who experience disabilities.

For 16 years, the Key Campaign has united people from across Alaska. We have brought together consumers, families and service providers to advocate for those who still wait for services.

In the beginning we were a small group. Every year we have grown. We now have local chapters throughout rural and urban Alaska, and we continue to grow. We have traveled to Juneau for 16 years and will continue to travel to Juneau for as long as it takes- for as long as people are forced to go without supports; for as long as the bureaucracy chooses to look at faceless statistics instead of human beings in need; for as long as families disintegrate in the reality of inadequate supports. The Key Campaign will be in Juneau. And afterward we will go back to our communities across Alaska and tell the people who wait why the bureaucracy fails to respond.

Please join us at the  
**Capitol Steps Rally**  
February 26, 2003  
At 12:00 noon

Please be one of those who chooses to help.

Please be one of those who sees the need and realizes the advantage of keeping together; who realizes the economic advantage of helping people become self-sufficient. Please join us as a member of the Key Coalition of Alaska.

## *Key XVI Campaign 2003*



*One Road*

*February 24, 25, 2003  
Juneau, Alaska*

*Community is the Key for  
individuals who experience  
developmental disabilities*

## What is the Key Coalition?

The Key Coalition is a statewide coalition of supporters, friends and advocates of Alaskans who experience developmental disabilities. They believe that the community is a place for all of us to forge our lifestyles, plan our future, experience friendship and love, recreate, work and dream! Community is the key that makes all of this happen for everyone. That's why the symbol of this coalition of people who advocate for an inclusive community is the **KEY**.

The four basic beliefs of the Key Coalition are:



Community is truly a place for everyone.



Individuals who experience a disability have a need AND a right to live in the community.



Individuals and their families must be empowered to assume a meaningful role in their neighborhoods, wherever they choose to live in Alaska.



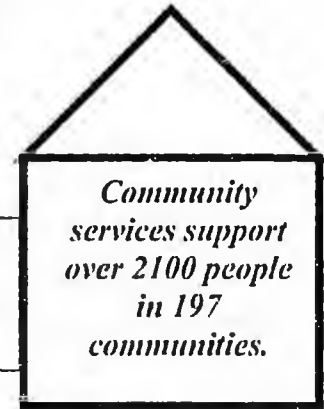
And, it is a primary responsibility of government to provide realistic, non-intrusive, non-segregating, community for **ALL** of its citizens, not just a select few.

The Key Campaign is Alaskans caring about Alaskans forging the way toward equal opportunity, accessibility, and an inclusive community for everyone who experiences a disability.

## COMMUNITY, That's what it's all about!



**COMMUNITY SERVICES ARE THE KEY FOR INDIVIDUALS WHO EXPERIENCE A DEVELOPMENTAL DISABILITY**



### Residential Supports

Accessible Housing  
Individual Leases/Home Ownership  
Low Interest Loans

### Employment Supports

Subsistence Activities  
Community Jobs  
Job Training

### Home Modifications

Ramps  
Accessible Bathrooms  
Stair Climbers

### Family Support Project

Family Resource Specialist  
Task Centered, Short Term Supports

### In-Home Supports

Respite  
Personal Care Attendants  
Chore Services  
Specialized Equipment

### TEFRA

Children Staying at Home



**Please,  
Support the  
Key Campaign!**



THE  
FOLLOWING  
DOCUMENT(S)  
ARE  
POOR  
ORIGINAL  
COPIES

Shirley Evans/Gerald Voigt  
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(907) 345-5163

RE: Lieselotte (Lilo) Evans-Voigt

Lilo is learning to care for herself, be a contributing member of a household and develop appropriate social relationships. For a 16 year old this may not seem like much to accomplish but I see my child making strides I never thought possible.

Lilo was born with multiple disabilities. Without Medicaid we could not have afforded her medical care. Major surgeries she's had include: 3 brain surgeries, spinal surgery to address severe scoliosis, and this past summer she had a toe on each foot amputated. In spite of all this, Lilo hikes, rides a bike 4 miles, ice skates, roller blades, and swims. She engages in one of these activities on daily basis, as we know how valuable these recreational skills are for improving coordination, balance, visual attendance, and gross/fine motor skills. As well there is also the pleasure she derives from movement, fresh air and the sense of accomplishment.

Lilo is severely autistic, has significant mental retardation, behavioral issues, is legally blind, incontinent, cannot talk and needs help with each and every thing she does. As parents all of us feel very protective regarding our children. I cannot imagine anything worse than watching your child being beaten. Far more times than I can count we witness and deal with this nightmare. Lilo engages in self-injurious behaviors that cause broken bones, bruises and blood. The damage she has sustained to her brain, body and senses is heart wrenching and depressing. Without services, which have allowed us to develop a team around Lilo's needs, I doubt she would be living with us. Though parenting Lilo is emotionally draining, losing her would be far, far worse. Thanks to Lilo's Medicaid Waiver, we have the help needed to set up and carry out a behavior management plan to teach her more appropriate communication and self-control. This requires expertise, hands on support and constant monitoring.

Caring for Lilo and assisting her in learning daily activities is complex. Every activity needs to be carefully considered and strategies developed that can be understood by Lilo and consistently followed by family and care providers. Every teaching goal needs to be examined as if we could think as Lilo does - Could she use this to injure herself? Will this help her or make our lives more difficult? For example, teaching her "sign language" for "more" began a self-injurious behavior of slamming her fists together with such force and intensity that her knuckles are permanently swollen and scabbed over.

In the past year, Lilo has begun doing household chores with hand over hand assistance from her care providers. Her younger sisters, Morgane, who is 13 years old, and Sophie, at 9, are ecstatic and feel it is long overdue. Lilo's list of what she can do is growing and includes: setting the table for dinner; helping prepare her lunch and snacks, filling and emptying the dishwasher; vacuuming the living room; cleaning the glass door; putting laundry into and out of the washer and the dryer; and sorting clean laundry. The assistance Lilo requires diminishes as she learns the steps involved in each of these chores. Eventually it is plausible she will be doing many of these activities independently as she has a talent for learning routines and responds very well to praise. Maybe someday she will even have a job!

I wish I could tell you Lilo will not require any more surgeries and that she is moving toward full independence. That is not true. She will need lifelong care in all areas. As parents we are doing everything possible to raise our daughter within her family. It is obvious without supports from our Medicaid Waiver this would be an impossible task for anyone. When you are deciding about changes to the Medicaid program please think of Lilo and ask yourself what her life would be like without her loving family, caring team and supportive services. We invest tremendous effort into creating a "good" life for our daughter and will continue to do this with your support. Not only does the Medicaid Waiver plan give Lilo opportunities to reach her potential and contribute; it is by far the most cost effective, humane and sensible approach. The cost to care for our daughter out of her home would exceed \$300,000 per year. Imagine what kind of life she would have in an institution where she would likely be drugged and restrained in a bed much of the time. Currently, Lilo has a varied, full life where she engages in pleasurable activities, helps within the family, continues to learn, and is dearly loved and valued by many people. All of this is possible due to services she receives from her Medicaid Waiver at a cost of \$65,000 per year. 17% of Medicaid recipients are comprised of people, like Lilo, with lifelong disabilities. The decisions you as legislators make determines not only the care they will receive but also shapes our society. Please ask yourselves what kind of assistance you'd want for your loved ones or yourselves. The services you judge our children as deserving; defines you as a legislator and as a person.

Thank you!

Butterworth  
Room

Intro 1. Maureen McClone - Anchorage

Key Condition

2. Wynn Levitt - Homer

3. Cary and Viron Webb and Jamie Polty - Anchorage

4. Kathy Marley - Fairbanks

5. Millie Ryan - Anchorage

6. Shirley Evans - Seward

7. Carla Norman and Cat Thompson - Seward

8. Debra Babcock - Fairbanks

9. Jason Scott - Eagle River

10. Maureen McClone - Anchorage