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Greetings,

Over the past seven years, the concept and idea of a National Youth Leadership Network (NYLN) for youth with disabilities has undergone and continues to go through many evolutionary changes. An emerging trend has begun; youth with disabilities have begun transforming from participants into leaders. Over the course of those first few years, the development of NYLN was marked by a transition from youth being the subject of the national conference to youth leading and developing the conference and having a say in what was discussed and presented. During that time, the Network was led by a few pioneering youth leaders who fought to have youth voices not only heard and included, but to have those voices be the guiding light for the identity of the Network.

The next big step in this development of youth power occurred when several youth leaders collaborated with the Oregon Health & Science University and Academy for Educational Development to obtain funding for the National Youth Leadership Network Development Project. This project, which recently transferred to Portland State University, is funded through the US Department of Education, Office of Special Education Programs with support from four other federal agencies (see side panel on the back for a listing). The US Department of Labor and Social Security Administration also give core funding to the Network. All of this support has allowed the Network to progress from an annual event guided by individual youth leaders to the creation of an organized Network of young leaders with disabilities committed to leadership development and education for all youth with disabilities. Over the past three years, the Network has developed a mission statement, outlined key strategic goals, adopted bylaws, conducted research studies, planned and hosted conferences and institutes, given over 300 presentations, and organized voter registration drives. Each year, in response to what youth say is important, the NYLN has

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**US Department
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and Prevention,
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**US Department
of Labor,**
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**Social Security
Administration,**
Office Program
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Research

**National Council
on Disability**

National Youth Leadership Network
Portland State University - RRI
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created a "Future Directions Agenda" that describes changes in attitudes, practices and policies that are needed in order for youth with disabilities to become successful adults. Most important, the NYLN also continues to form stronger connections with those who matter most, youth with disabilities.

The Network is now embarking on a new type of evolution through this newsletter and other activities to make sure, year-round, that the voices of youth with disabilities and the issues we are faced with are expressed to those making the decisions that will affect us all.

As the Network develops, we are continuously identifying new technologies and other ways to ensure that all youth with disabilities have the opportunity to achieve their unique, maximum potential and to empower others to do the same. For example, we have recently launched a new virtual community titled *Inside NYLN* that makes it easier for members to communicate and work together. For example, new conference participants are now able to communicate with other participants and members prior to the conference as well as to have a say in specific details of the conference. Additionally, it will provide an opportunity for participants to review conference material ahead of time so that their transition to the conference will be easier and more natural.

This newsletter will serve as a resource to all who are interested in what youth with disabilities say is important and who want to learn what tools are important for their journey. But beyond these goals, we want this newsletter to be a call to action for all those who believe in youth leadership in order to ensure that this idea continues to develop. Without federal agencies, private organizations, mentors, family and, most importantly, the youth, this newsletter, this organization and this belief would not be a reality. We encourage you to read the material and learn, but more importantly, communicate, and provide feedback and comments so that the NYLN can continue to grow and youth with disabilities will forever be empowered.

Sincerely,

Peter Noonan Squire, Chair
National Youth Leadership Network

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Network Activities and Updates

2004 Conference

The National Youth Leadership Network (NYLN) recently concluded its 2004 Conference "Learning, Living, Leading: Youth with Disabilities Continuing the Legacy" held in Washington, DC, July 24-27. Sixty-six young adult leaders from 38 states, Washington, DC, Guam, Puerto Rico and Siapan, all between the ages of 16 and 28, came together to share their insights and experiences about issues such as employment and college options, Social Security benefits, assistive technology, and disability history.

The 15 members of the NYLN Governing board worked tirelessly to bring the conference together and ensure its success. However, it would not have possible without our wonderful speakers, federal agencies members, private contributors, and most importantly those youth who took a risk and applied to attend the conference.

Public Information

The Public Information Committee has been involved in the design and creation of this first ever newsletter from the Network and it continues to develop and improve the website and create and distribute materials for the public. Additionally the Committee was very active in leading the selection of the 2004 conference participants.

Membership

The Membership Committee supports the efforts of our members and other youth interested in getting involved in community projects. Most recently the Committee lead a voter registration project. Network members were asked to go out into their communities and register ten individuals to vote. The Committee will be working on improving connections and interaction among members over the next couple of months, and it has developed a plan for youth to work together on their goals following the conference, which it will lead. Finally, the Membership Committee led the Education and Employment day at the 2004 conference.

Research

The Research Committee is very involved in overseeing the first research study ever conducted to investigate and compare the experiences that contribute to leadership development by young people with and without disabilities. Surveys are being completed by youth with disabilities in leadership roles, youth with disabilities who are not in leadership roles and youth leaders without disabilities. The Committee hopes to have the data collected and analyzed over the next few of months. The Committee was also in charge of all the conference logistics, from participant travel to food.

Mentorship

The Mentorship Committee has been actively involved in identifying national mentors for Network members. They also spent a considerable amount of time organizing one of the most notable days of the conference, Disability Awareness. Finally, the Committee has started a plan to connect 2004 conference participants to mentors in their home communities.

Funding

The Funding Committee planned the Healthcare day at the 2004 conference in addition to developing several policies for the oversight and distribution of Network funds. These policies describe how funds can be requested by members to support their Network presentations and consulting (Resource Consultants). They also describe how Governing Board and Committee members can request general funds to support their activities, and can receive small stipends in honor of their contributions to the Network. The Committee is currently working on developing a letter to send to corporations and private foundations requesting contributions to continue the Network's activities.

If you are a youth with a disability and would like to find out how you can get involved in these activities, please contact Kristen Jones at lilkit@aol.com.

Member's Circle

Please send all Member's Circle submissions, requests and comments to Kristen Jones at lilkit@aol.com or Elizabeth Guerrero at guerrere@pdx.edu or by mail to: Elizabeth Guerrero, Portland State University - RRI, PO Box 751, Portland, OR 97207

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3. Member Extraordinaire
4. Book of the Quarter
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On the Web

You feel your pores open up, sweat dripping down your chin...anxiety sets in and the last thing you think is, "I have never ever seen a wheelchair drop 13 feet into a swimming pool except in a rare occasion of bad driving!" Well, this web page brings to life all those things in disabled athletes taking on extreme sports <http://www.farfromwalkn.org/>.

The National Collaborative on Workforce Development for Youth is a source for information about employment and youth with disabilities.

<http://www.ncwd-youth.info/>

What They Said...

"Mr. Dart told me that one of his favorite articles about him was entitled 'What's So Great About Justin Dart?' It seemed a strange selection to me, given all that he has accomplished and contributed. The article speculated about how various achievements might be explained away. But that was only to get to the final point: What's so great about Justin Dart? Answer: he loves people. That has nothing to do with resources. That's just who Justin Dart is -- to the core. His ability to love people, all people, is the symbol, to borrow one of his phrases, of a true American patriot."

-Jonathan Young, 2001

Member's Circle

Member Extraordinaire

Member of the Quarter:
Josie Badger



My name is Josie Badger; I'm 20 years old and am a sophomore at Geneva College, in western Pennsylvania. I have a rare form of muscular dystrophy, which is called myasthenia gravis syndrome. It causes generalized weakness of my voluntary muscles. My service dog, a black lab named Vito lives with me at college. I am vice president of the sophomore class at Geneva and on hall council. I am also a 4-H leader, vice president of Lawrence County Disability Council and a resource consultant for NYLN. This summer I am interning for the Education Law Office in Pittsburgh.

One project I am excited about being involved with is the Pennsylvania Transition Conference at Penn State University. This conference will address services and supports that assist students in transitioning from high school to jobs or higher education. I will be presenting a workshop about college life and managing health care needs while living away from home. I am also working with Children's Hospital of Pittsburgh to establish a transition support group that will help youth in the Pittsburgh area plan and be successful after high school.

Another project I am working on is "Every Child Deserves a Home and Family", sponsored by Pennsylvania Protection and Advocacy Children's Project. I was involved in the planning phase of the conference and was a speaker at it. This conference initiated a movement to get families the support they need to keep children that have complex medical needs at home. There are almost 3000 children in Pennsylvania with special health care needs that are institutionalized.

There are issues in health care support, community resources, insurance, public policy, and education that must be addressed. The work that must be done is overwhelming, but this dedicated group is tackling them to allow children to grow up at home with their families. Feel free to contact me at casb2000@yahoo.com.

Do you know someone who has done something cool since attending the NYLN conference? We want to hear from you! Please nominate someone that is a member of the NYLN and briefly tell us why you think they should be featured in this section.

Member's Circle

Book of the Quarter

No Pity: People with Disabilities Forging a New Civil Rights Movement by Joseph P. Shapiro.

Movie of the Quarter

Matchstick Men--A professional con man struggling with an obsessive-compulsive disorder meets the daughter he never knew he had, inadvertently jeopardizing his very organized and artificially controlled life.

Opportunities

1. Regional Contacts

We are looking for youth to serve as his/her region's NYLN liaison.

Responsibilities include:

1. Being point of contact for other consultants in your region
2. Keeping us informed about what is going on in your region
3. Assisting us with identifying resources.

The region structure is as follows: Midwest, North Central, Northeast, Southeast, Southwest (which also includes US Territories, Puerto Rico and Guam), and West (which also includes Alaska).

Contact Kristen Jones at lilkit@aol.com to obtain further breakdown of regions.

2. Contests!!!!

- Enter to win a \$25 Target gift card by helping NYLN design a new logo. All submissions must be in by January 31st, 2005.
- Help us name and develop a logo for this newsletter. Prize offered for the best entry. Please submit your ideas by January 31st, 2005.

Member's Circle

Information

1. Bender Consulting Services, Inc.: www.benderconsult.com

Bender Consulting Services, Inc. is a for-profit company that focuses on providing competitive employment for Americans with disabilities. "Americans with disabilities will never, ever be free until they have competitive employment."

Make sure you listen to *Disability Matters with Joyce Bender* on www.voiceamerica.com every Tuesday from 2:00 to 3:00 EST to hear about our history and our leaders--if you don't know--you won't grow!

2. Kids As Self Advocates (KASA): <http://www.fvkasa.org/index.asp>

We serve as youth advisors to many Family Voices activities at the state and national levels. We represent the voice of youth living with disabilities and chronic health conditions by speaking at public events, hearings, to governors and with other policy makers. We also educate medical students and physicians, and fellow students at our schools.

Kids As Self Advocates (KASA) is an organization created by youth with disabilities for youth to educate society about issues concerning youth with a wide spectrum of disabilities and special healthcare needs. KASA believes in supporting self-determination, creating support networks and proactive advocacy for all youth with disabilities in our society.

We model leadership and the power of self-advocacy. We are active in our schools, communities, families and, in some cases, places of employment. We are proud to have overcome obstacles. We share our message with other youth who have disabilities or chronic health conditions, and with our typical friends and peers.

National Advisory Board of KASA--The Board of KASA advises policy for the KASA organization as a whole, including activities like the website, newsletter, and possible meetings. This Board serves several purposes: it leads the programming for KASA; it provides an opportunity for youth to sharpen their leadership skills; and it is a valuable resource to the media, professionals and other young adults regarding issues concerning young adults with special health care needs.

We are currently seeking new board members to represent the youth voice between 14 - 24. If you are interested please contact, julie@fvkasa.org or ortizn@fvkasa.org

Through the Window of...

A Personal Youth Story Written By Katrina Carter

Life is rarely fair. Often, we are face with overwhelming obstacles that seem impossible to overcome, but giving up at these times is the worst possible thing you can do for yourself. Before my life-changing accident, I was in kindergarten and thrilled to be riding my bike without training wheels. I was like every other five-year-old. In fact, I was a tomboy and loved to be outdoors riding my bike with my long blonde hair flying in the wind. I felt so free. I really enjoyed riding bikes with my neighborhood friend Allison, playing with friends at recess, helping my dad in the garden (I loved to play with worms), and picking raspberries with my family during the summer.

One day that same year, my life changed forever when I fell off my bike while riding with my dad in a neighborhood near our home. I was riding without a helmet when I lost my balance going up a gentle sidewalk curb. I flew headfirst over my handlebars and landed on the side of my head. **No cars were involved.** My dad rushed to me when he saw me fall but could find no serious injuries; just a scratched knuckle on my hand and a very small bump on my head. There was no bleeding or loss of consciousness. He rushed to the nearest house and called my mom to come pick us up. When we reached our home, mom called the doctor who said it was okay to let me go to bed if I felt like it, but to wake me every hour. After a couple of hours, I started vomiting and later that evening I slipped into a coma. Since that day I have not felt the wind blowing my hair while riding my bike. I didn't know I would never have that kind of freedom again.

I remained in a deep coma for five months. To sustain my life the doctors put a tube in my trachea so I could breathe and a tube in my stomach so I could get nourishment. I underwent several brain operations in hopes of saving my life. They didn't expect me to live and certainly never to come out of the coma. I was placed in a nursing home with the elderly; *I was only six years old.* I required such intensive medical care that I was not allowed to go home. However, sometime in August of that year I showed signs that my brain was beginning to recover. My eyes could follow things, but other parts of my body would not move. When I woke, it wasn't like in the movies. I couldn't talk or move my body. It was like I was a statue! I was unable to understand a single spoken word. I didn't even know what the word mom meant. I was unable to communicate with the most important people in my life.

Although the doctors said I would never be able to walk, talk, or eat again, they placed me in rehabilitation at Children's Hospital. During my twenty months in rehab, I slowly relearned how to walk, talk, and eat. To date, I have had a total of at least sixteen surgeries all related to the accident.

Today, I am twenty-three years old. Each day presents new challenges and frustrations. I don't have a boyfriend; never have had a date or been invited to a school dance. In fact I don't have many friends. I no longer see my best friend, Allison. I won't drive a car. I can't do all the things twenty-three-year-olds do for fun. I can't put on my socks and shoes; I can't wear regular jeans with zippers. It's hard for me to wash my hair, even while sitting in my special shower. I can't walk and carry things at the same time, because I need both hands for my crutches. I can't bend because I have two steel rods in my back, due to scoliosis from my brain injury. I don't talk on the phone very often because of my speech difficulties and because of the energy required. When I fall, it is very difficult for me to get up. I don't know if I will ever get married or be able to have children or even to live on my own. Those who assist me invade my personal space constantly.

In spite of all these obstacles, I never stop trying. I continue to have physical therapy three days a week to help me regain and improve my abilities. Although I will never gain back all of them, I will continue to work hard. I am from Kenmore, WA, and a graduate from SAS, the Secondary Academy for Success, in the Northshore School District. Currently, I am a student at Cascadia Community College, where I plan to get the Associate in Integrated Studies. I love school, and am an excellent student. I have also gone back to Washington, D.C. four times attending or helping in the planning process of conferences like the NYLN. I do keep busy and have myriad interests, including reading mysteries, sewing, writing, gardening, taking walks, and doing genealogy and puzzles. All of these activities are possible because of immense amounts of courage, determination and perseverance; however, I would not be where I am today without the love and support of my devoted family and a good sense of humor.

Disability Leader Profile

Yoshiko Dart

Since marrying Justin Dart, Jr., in 1968 she has been his full partner in promoting the rights and empowerment of people with and without disabilities in the area of disability policy and years of citizen advocacy for civil rights, independent living, ADA, universal health care, and the election of pro-disability rights candidates.

What is your name and please give a description of yourself?

Yoshiko Dart, black and gray hair, dark brown eyes, 5'4" tall, and 65 years old

What is your job, and what do you do on a daily basis?

Full time volunteer for civil and human rights and the empowerment of people with disabilities

How did you get involved in the area of disability?

My late husband, Justin Dart, Jr., was a wheelchair user.

How would you characterize your life, and what has made you successful and helped you develop as a leader?

I took over my mother's role (she died when I was young) and helped my family of alcoholic father and two younger sisters and learned how to be responsible in a poor situation. I believed in getting education and wanted to be an international minded person while living in a mountain village of Japan back in the early 1950s.

When you were a young individual what was one of your fondest memories, and why?

Communicating with some Americans in English (I lived in the mountain village of Japan with no TV). I felt my life had opened up beyond Japan.

What are the greatest challenge currently facing individuals with disabilities? How do you think youth with disabilities can help face this challenge?

Ignorance and fear of the unknown among all people about disability – a natural characteristic of being human – therefore prejudice and discrimination. To realize the power and responsibility in you is essential. A revolution of individualized empowerment is the answer.

What do you think is the most important advice you could give to a young person with a disability who wants to be a leader?

Find your own truth, believe in your power and live your dream. Don't wait for any savior to come and give you happiness. You need to go out and work hard. Take complete responsibility for what you do, good or bad.

If there was a youth sitting in front of you and wanting to know what you thought the important thing in life is, what would that be?

My answer will be the same as the previous one. Because I believe everyone should be a leader and become a truly loving human being.

The goal in life: struggle to improve your own life and others' everyday in most truthful, peaceful and loving manner – that I think is a profound happiness.

When you think of youth with disabilities what type of characteristics or personality traits do you think it is important to have, what type did you have when you were young and how did they change when you got older?

Positive, forward looking, cheerful, passionate, truth and justice loving, positively frank, full of fighting spirit, responsible and loving personality will be ideal not only for youth with disabilities, but also for everyone in the world.

I was very much action oriented and made some big mistakes. I got wiser through those tough experiences. I learned a lot from Justin's lifelong struggle to live his own truth and love humanity in everyone including his enemies.

What do you expect or desire from youth leaders with disabilities?

When you are not successful nor happy, do not just blame parents, teachers, counselors, medical professionals, unfriendly classmates, neighbors, politicians, business people, religious people, media people, foreigners, temporarily able-bodied people, different ideology, society, etc. and on and on. Don't wait for them to change. First of all you need to figure out how to get up and change yourself and continue to change yourself, therefore change the society of which you are a part. Don't expect or wait for anyone to come down from the sky to save you.

When you make friends alike and help each other, you will be truly empowered and become a leader. Make your powerful circle bigger and bigger. Nobody can take away your real power.

Lastly, what do you see as your role in helping emerging leaders, how are you helping build the leaders of the future?

By telling you the truth; by encouraging you to meet with great politicians and leaders of different organizations; by actually introducing you to such individuals whenever opportunities come up; by encouraging you to fully get into politics; by urging you to take on responsible jobs and assignments and produce good results, I believe you will develop yourself well. I would like to assist you in anyway possible so that you will recognize and feel your own power (potential) and responsibility and start leading the revolution of individualized empowerment.

Stop being spectators and become decision makers and CEOs of your own lives. Don't be afraid of making mistakes and lead on no matter what.

I POWER!