

# Miniwakan Tiyospaye E-News

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## FEATURES

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### About Our Names

Welcome to the first edition of the **Miniwaka Tiyopsaye E-News**. We are produced monthly by Spirit Lake Consulting, Inc., a firm founded and with headquarters on the Spirit Lake Nation. This newsletter is part of the **Disability Access** training program for people with disabilities and their families funded through the National Institute on Disability Rehabilitation Research (NIDRR).

Our newsletter name = Miniwakan: means 'spirit water' or 'Spirit Lake' in Dakota.  
Tiyospaye – is the Dakota word for family.

Dibaajimowin siipiising is news from Turtle Mountain, a regular column written by Willie Davis, our site coordinator for **Disability Access** on the Turtle Mountain reservation. Dibaajimowin means news and "siipiising" means little creek that sings. Put together is how you would explain Turtle Mountain Ojibwe news. Where is Turtle Mountain in there? Nowhere, because that is not what the Anishinaube (first people) called themselves or this area. There is a spring that runs through the reservation, which is how the people originally referred to themselves.

## You Don't Know What You Don't Know

By Evelyn Klimpel, Parent

Something was wrong with my baby boy. Being a long-time educator I felt foolish for not knowing about early intervention. Yes, I knew enough about development milestones but not about birth to three service providers. I kind of heard about infant development but I really didn't know what they did. I thought they only served children with disabilities whose families were low income. Did I ask? No



**Why you say?** I was scared of the answer and I think my pride got in the way. I have a tendency not to ask for help from anyone. I want to try to do it myself. Well this time trying to do it myself wasn't working. During the diagnosis phrase of finding out exactly what was wrong with our child lead us to asking a relative in the nursing field for help. Meanwhile, at the same time I worked for an agency whose focus was disabilities. In fact the Infant Development Program was a couple doors away. Did I walk down the hall and ask for their help? No

**Should I have asked for help?** Yes! My son was having strange temper fits at night and nothing, no nothing we did helped comforted him. He screamed until he played himself out. I feared he had some kind of mental disorder because he was a normal kid during the day but not at night. So I let my fear of a stigma of mental illness get in the way of me seeking help for my child. *At that point, I didn't want to know what I didn't want to know.*

**When did I finally seek help?** When my son starting walking with one crooked leg. We reasoned that it would straighten as he grew and it was nothing to worry about but I knew better. The crooked leg and nightly temper fits kept me churning inside. One fall day I took my son to the doctor because he had a bad cold. It was at that time that I finally blurted out that I thought something was wrong with my son's leg but I didn't mention the nightly fits. She looked at his leg and immediately scheduled an x-ray. The x-rays confirmed my worst fears. Something was wrong with my son's leg but what? *I needed to know what I needed to know. But how?*

**Where is the starting point?** Well, here is where you will learn from my mistakes in getting services for my child. My son was two years old and eligible to receive services from the Infant Development Program (IDP). Infant Development supports activities for infants (birth-3) who are developmentally delayed, high risk, or at risk. In addition, they provide in-home programming and infant stimulation activities for eligible children. And most importantly to my family was Infant Development would have assisted us with finding information, and locating services for our child's rare bone disease. As you see, I should have knocked on their door and asked to apply for their services. The key word here is ASKED. I have learned that if parents don't ask the right questions they don't receive all the services available to them.

**What services?** Below is an example of what services would have been available to us if we had been enrolled in an Infant Development Program. I have asked Ms. Ellen Mellard, M.S. who is a OTR, Occupational Therapist/Clinical Instructor, University of Kansas Medical Center, Kansas

City, Kansas to be my “pretend” service provider. We are using the Hilton SpecialQuest Family – Service Provider Collaboration Model.

**Ultimate Goal:** To be a parent who knows my rights for my child and my family. Therefore, I as a parent am a leader in making decision regarding my child and family. Informed decision-maker and who participates as a leader for my family, programs and community in working with service providers.

## **What we bring to build a good working relationship**

### **1. My Family System**

- Caring parents
- Caring big brothers
- Strong extended family (Aunties, Uncles, Grandparents and tons of cousins)

### **Ms. Ellen Mellard**

### **Service Provider System**

- Training and expertise from my education and experience
- Commitment
- Knowledge of systems/laws
- Discipline specific knowledge as an Occupational Therapist (such as feeding, positioning, sensory processing, motor development)

### **2. Building our relationships**

- With the medical world
  - I found the best way to get answers was to call our specialist. If we couldn't get him at work we would call him at home. Once he even called us because we hadn't showed up for our appointment.
  - The second best person was our specialist nurse. She was our direct line to him.
  - I found that working with the same person at Indian Health Services was the best way to get what I needed.
  - In order to continue our daycare services, we had to help her with our son's care. My husband would stop in regularly to assist with toileting.
  - We provided transportation for our son to school. It wasn't until he was in the third grade that we found out the school could pick him up with a bus with a wheelchair lift. We asked . They gave. I wished we had asked sooner! It would
- Listening to and learning about the family
  - Learning about culture
  - Pacing: respectful and sensitive to how information is gathered and shared with family
  - Attending appointments with the family
  - Building relationships with medical community/child care providers/ community resources

have saved my back.

### **3. Gather Information and Resources**

- The internet is a valuable tool to use but remember not everything you see in print is true.
- Internet support groups
- Asking other parents of children with disabilities about what services are available.
- Locate financial support and resources for the child and family
- Link family with other services, other families, other agencies
- Request records from other providers
- Answer questions
- Discuss resources and transition at age 3

### **4. Develop Collaborative Plans**

- Our specialist gave us the option of when to schedule surgery. He would say that this needs to be done but let us set timelines.
- We learned that doctors do not know everything so if something doesn't feel right question them and get a second opinion.
- To always make sure Indian Health Services approves the procedure in writing.
- Inform family about the process of developing plans
- Inform family about legal rights – what is required, how requirements are met etc.
- Resources and Priorities are defined
- Develop the plan with the family – IFSP or Family Partnership Agreements
- Process should be inclusive of all people/agencies working with child and family
- Family determines outcomes

### **5. Implement Collaborative Plans**

- Indian Health Services provided daily care supplies but only enough supplies for one week. I asked friends, and family members to pick it up for me because I live off the reservation.
- Always make sure Indian Health Services is kept up to date with our sons procedures. We learned to sign all those release forms so the information is sent to IHS or we were responsible for the medical bills.
- We kept all our scheduled appointments with our son's doctors. A missed appointment could delay our son's recovery. I would schedule the appointment so it would work into our family schedule rather than having IHS do it for me.
- Intervention is provided within the context of the family's and child care provider's routines and activities
- Continual brainstorming of what is and what is not working for family and child
- Communication is ongoing

- Many times I found that asking for a copy of the medical records speeded up services.
- I found it difficult to manage all the medical and insurance paperwork. I did learn to make copies of everything.

## **6. Establish and Maintain Collaborative Leadership**

- We trusted and loved our son's specialist because he would explain clearly what was going on.
- We learned to write down all our questions the night before our doctor appointments.
- Currently, we are back to Step 1 because our specialist moved out of state. We are now dealing with Gillette Children's Hospital in St. Paul, Minnesota.
- Joint trainings with providers and families
- Family provided opportunities and support for participation on Interagency Coordinating Council and Policy Council
- Family assists in evaluation of programs

### *Hilton/Early Head Start Training Program – Development of Family – Service Provider Collaboration and Leadership: Getting Started Model, 2005*

A year ago, Ellen and I demonstrated this model at a SpecialQuest training. As I listened to Ellen talk about all the help an early interventionist would have been to our family, I felt sad. I think about all the struggles our family went through alone. Life would have been still tough but at least we would have had someone who knew the system to share the journey.

**You don't know what you don't know** so take that first step by telling your child's teacher or daughter that you think something is wrong. Ask to be referred to the Infant Development Program (Birth – 3) for services. Finally, you can ask Infant Development Services to put you in contact with other families in the same boat. I found other families as an excellent resource to ask about what questions need to be asked to get those services!

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DIBAAJIMOWIN SIIPIISING

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## **dibaajimowin siipiising – News from the little creek that sings**

*By Willie Davis, SLC Consultant, Turtle Mountain Site Coordinator*

### **Independent Living Centers & the Need on American Indian Reservations**



It has been my experience over the last 25 years living my life in a

wheelchair that the Independent Living movement in “Indian Country” needs to take a hard and firm look at how their disabled tribal members are part their community. It is about time that tribal officials make disabled and special needs people on the top of their priorities list. My personal experiences include serving on the North Dakota State Independent Living Council (SILC) for over 6 years. This opportunity allowed me to be involved in the development of a State Plan for Independent Living that clearly recognized the need to provide more direct services to rural communities and, especially, reservations.

#### **What does an Independent Living Center do?**

*“The purpose of Independent Living services is to eliminate barriers and provide assistance to individuals with disabilities so they can live and work independently in their homes and communities” – [North Dakota Department of Human Services](#)*

While serving on this Council I gathered much understanding of the need for Independent Living Centers, especially on reservations in North Dakota. Tribal members and Tribal officials need to consider these necessary services that these Centers provide. Specific services may be different across centers, but very common services are:

- **Independent living skills training** – using public transportation, budgeting, basic computer skills,
- **Personal assistance services** - recruiting, interviewing and referring consumers to personal assistants who can provide personal care services and housekeeping for people with disabilities.
- **Housing assistance**, including advice, assistance with loans and resources for changing homes to meet the needs of people with disabilities with ramps, side-bars on walls, wider doors, etc.
- **Transportation assistance**, including vouchers for taxis or other transportation to doctor’s offices, shopping and other needs,

- **Peer Support Program** - designed to promote positive coping skills for persons with disabilities, including individuals with newly acquired disabilities.
- **information** about disability issues and referral to services for persons with disabilities.

Also there is a requirement that more than 50% of the center staff must be people with disabilities. Given all of these very positive facts about Independent Living Centers, I am very concerned that there **there is not one Independent Living Center on any reservation!** I have served on many local and national groups that share the same concerns about the ability of tribal members to receive necessary information and services that is vital to their everyday lives. If such a center was available disabled tribal members could then receive the necessary services from a local office. Staff members from the office could deliver services for tribal members with limited mobility in their own homes. This would sometimes be needed given the lack of availability of transportation, which in many cases is a problem (**but, this is another matter for discussion and another article for a future newsletter!**)

I have lived most of my life on or near the Turtle Mountain Reservation. I have witnessed first-hand how persons with disabilities living on the reservation either cannot get the necessary services in a timely manner or many times have to get information on services second hand (from a relative, friend or local agency). **This I feel is not right !** If there was a centralized and locally available Center that could pull together all the information, services and communication needed for tribal members with disabilities then Tribes will have inclusion as full members of the community for **all Tribal Members!**

One way for tribal communities/reservations to be **pro-active** in developing such a Center or Disability Center would be to lobby their legislatures and tribal officials to discuss governmental set-aside for Tribal Independent Living Centers. We must continue to move forward in making our voice heard, so that people with disabilities needs and concerns are made a priority within our local communities, and at the state/national level.

Currently there are 4 Independent Living Centers and 2 Outreach offices serving the state of North Dakota. Although we presently do not have such Centers on tribal reservations, it is good to maintain contact with your local state Center. Listed below are links to those 4 Centers and Outreach Offices serving the State of North Dakota, please click below to contact the nearest center serving your area:

**(1) Freedom Resource for Independent Living, Inc. (Fargo)**

1-800-450-0459 <http://www.702communications.com/~freedomrc/contact.html>

freedom@moorheadcity.com

Serving the counties in the Southwest area of North Dakota and Western area of Minnesota.

**(2) Dakota Center for Independent Living (Bismarck)**

1-800-489-5013 <http://www.dakotacil.org>

royces@dakotacil.org

Serving the counties in the South Center area of North Dakota

**(3) Independence, Inc. Center for Independent Living (Minot)**

1-800-377-5114 <http://www.independenceinc.org>

life@minot.ndak.net

Serving the North Central Counties in North Dakota

**(4) Options Resource for Independent Living (East Grand Forks)**

1-800-726-3692

randy@myoptions.info

Serving the counties of North East North Dakota and Northern Minnesota

Branches:

Dickinson Branch

(701) 483-4363

Jamestown Branch

(701) 252-4693

“For most of us, living independently is not a new concept. We take it for granted; we choose where we live, work, and play. It is, however, less than thirty years since that concept became associated with people who experience disabilities.” To learn about Ed Roberts, the individual who started the Independent Living movement, [click here.](#)

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CONGRATULATIONS

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**Dr. Longie Earns Doctorate**

Congratulations to **Dr. Erich Longie**, President of Spirit Lake Consulting, Inc. who recently became the first enrolled member of the Spirit Lake Sioux Tribe to earn a doctorate.

Dr. Longie’s dissertation is a qualitative study of characteristics of successful tribal colleges and their impact on the social and economic development of their communities.



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## And now, a word from our sponsor...

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End of E -Newsletter

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### **Spirit Lake Consulting, Inc.**

P.O. Box 663

314 Circle Drive

Fort Totten, ND 58335

(310) 717-9089 Tel.

(310) 496-2068 Fax.

<http://www.spiritlakeconsulting.com>

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