

# Building (or re-building) a State Advocacy Organization

People First of Nebraska, Inc.  
Presented March 22, 2016

This presentation was developed with the input of the entire Board of People First of Nebraska, Inc., its local and state advisors, and staff

# Introductions



Travis Schaffer

- PFN Vice-President
- Nebraska Lead, Heartland Regional Self-Advocacy Network
- Chick Magnet



Kathy Hoell

- PFN State Advisor & Parliamentarian
- Executive Director, Nebraska Statewide Independent Living Council
- Queen of the Universe

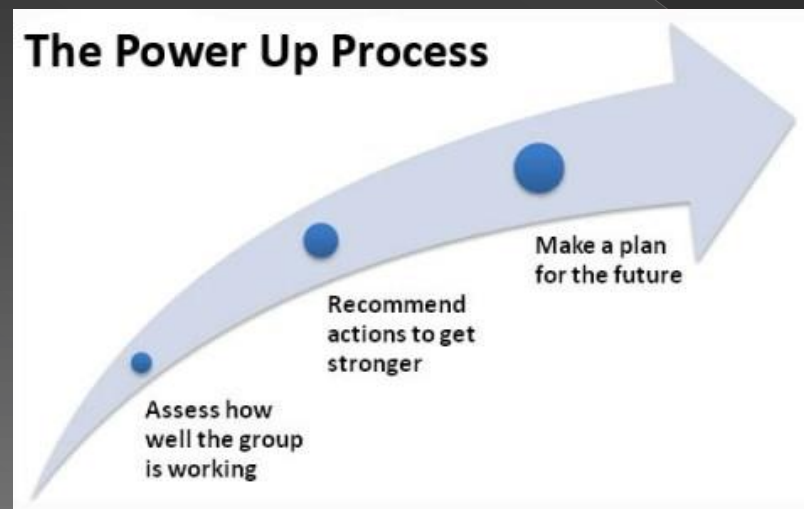


Kellie Ellerbusch

- PFN Lead Staff Support
- Nebraska LEND Training Director/UCEDD Associate
- Loyal Minion & Ally

# The Saga Begins...

- Power-Up Site review January 2012
  - > Evaluation and Assessment service for self-advocacy organizations
  - > Project of the Human Services Research Institute  
<http://www.theriotrocks.org/services/power-up>
  - > Paid for by the Nebraska DD Planning Council



# The Situation

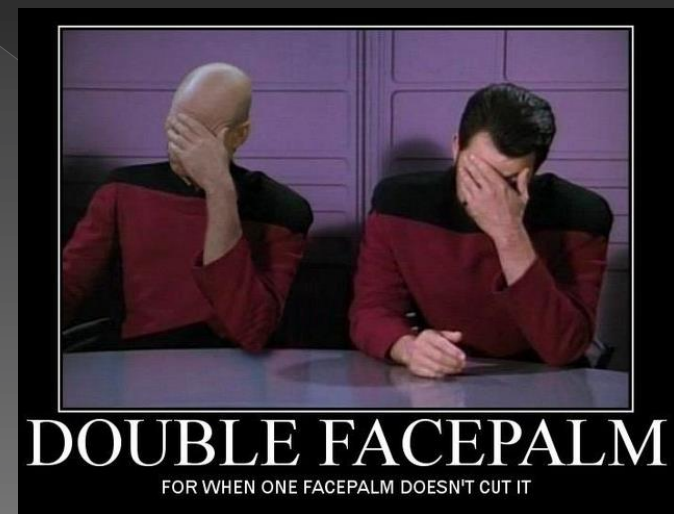
- State Advisor quit less than 6 weeks before our annual convention
  - > No one knew what had been done/not done
  - > Same presentations year after year
  - > Low participation – “Social Club”
  - > Convention expensive-attendance dropping
- Low Morale / Anxiousness / RUMORS!
- Some chapters dissolved, PFN Vice-President and some advisors quit

# The Situation

- Officers and Board did not know what their roles/responsibilities were
  - Meetings were boring & controlled by the state advisor and some chapter advisors
  - Officers rotated offices – no new leaders
  - Nominations and Elections scripted by some advisors – members told how to vote
  - The Board was divided and fighting
- By-laws had not been updated since 1984
- TOO MUCH DRAMA!

# The Situation

- ◉ No new chapters organized for many years
- ◉ No communication between chapters
- ◉ Little support from other disability groups
  - PFN had no credibility or perceived value
- ◉ We did not possess any financial or organizational records
- ◉ No money and invoices not submitted for payment
- ◉ Grant application 3 months past due



# Step #1 Self-Determination!

- Focus group with full membership
  - > At the convention, the full membership met to voice all their questions, concerns, and make lots of suggestions
    - Notes from this meeting were used to write the goals of the grant application to the DD Planning Council
- Members also filled out a written satisfaction survey
  - > MORE great ideas and suggestions
- Research materials from other SA groups
  - > Officer roles, by-laws, mission statements (Thanks Missouri!)

# Step #2 Find Our Allies

- Officers reached out to allies in other organizations to be advisors
  - > Each advisor had specific skills needed
    - Non-profit management, Rules of Order, Administrative support, institutional knowledge, comedy relief, etc.
  - > ALL advisors were volunteers, offered different resources, and were supported by their organizations
- A CPA volunteered to audit books
  - > Fiscal guardian for one of our officers
  - > She continues to audit financial operations
- An Attorney volunteered to for HR issue
  - > Friend of and attorney for one advisor's family business



# Step #3 Officers Take Charge

## ● Emergency Officers Meeting

- > Attorney advised Officers, who then made HR decisions with advisor support as requested
- > CPA submitted financial audit report
- > Board appointed a new Vice-President (Welcome Travis!)
- > Officers discussed what needed the most immediate attention and decided what committees needed to be formed to take on all the tasks (by-laws, convention, brochure development, recruitment, nominations/elections)

## ● New Staff Support person

- > NOT an advisor but a person to take direction from and support the Board and Membership.
- > Board Developed a job description and interview questions
- > Officers interviewed three candidates and selected a staff support person in May, 2013

# Moving right along, until...

- President resigned due to illness (Welcome President Travis!)
- By-laws were unmanageable
  - Suspended until new ones were adopted (we used Roberts Rules of Order in the mean time)
- Staff Support person was let go
  - Expectations not being met, decisions made without consent of the officers or board
  - Officers made the difficult decision and delivered the news to the individual with the support of advisors

# Step #4 Review and Adjust

## ● New strategy for Staff Support

- Too big a job for one person – needed an administrative person and a recruiter
  - A division of duties was approved by the officers
  - Interviews and negotiations were handled by the Officers and they were tough!
  - Goals of the staff support person's primary employer aligned with the goals of PFN so we could leverage resources

## ● New brochure developed for recruitment **aka: Kellie screws up big time**

## ● Display boards to promote PFN

- Many organizations gave us booth space for free



# Three years later...

- Officers are elected openly and honestly and by MEMBERS only
- New Officers and Board members receive training on their role/responsibilities
- We are learning how to disagree and compromise and still remain positive
- We adopted new by-laws and follow them
- Conventions are affordable, national speakers are exciting, and attendance is rising!
- All convention presentations MUST be co-presented with a person with a disability

# Three years later...

- Other organizations are providing significant financial support for the convention and inviting PFN officers to participate in and present at conferences and panels, and to serve on boards and committees
- Over \$20,000 in the bank
- Grown from 9 to 13 chapters with three more expected to launch this spring/early summer.
- Cross-pollination between chapters and with advocates in other states
- Participating in the Self-Advocate Coalition of Kansas conference in June and Kansas Leadership Center training in August

# Three years later...

- Three support staff (Eastern, Central, and Western Nebraska) help organize new and support existing chapters in our areas
- DD Planning Council increased funding by \$7,000 for transportation for chapters to attend Board meetings and to support PFN members to attend national and regional conferences.
- Facebook page with over 300 followers
- Web site launching April 18  
[www.PeopleFirstNebraska.com](http://www.PeopleFirstNebraska.com)

# What's Next for PFN?

- More visibility in the disability and general communities
- More participation in statewide PFN activities by local chapter members (not just Board members)
- More Advocates at disability trainings, committees, workgroups, etc.
  - Name them and shame them if they are not including advocates AT ALL LEVELS!
  - Supporting Advocates means paying for their travel and PAYING them, just like other professionals are.
- Training and support for advisors
  - Supporting without taking over, the self-awareness to know the difference...and the humility to apologize when you mess it up (and you will)

# Lessons Learned

- Start with the **membership** (NOT professionals, parents, advisors, or other disability organizations or agencies)
  - If it's not working, ask yourself, "who is running the show and setting the agenda?"
- Get the Advocates front-and-center immediately.
- Identify your strengths and weaknesses
  - An outside evaluator can help
  - Find advisors/supporters who can address those needs and share your values of self-determination
- Focus on LEADERSHIP training and experiences, not just advocacy training



# Lessons Learned

- Consider contracting for staff support instead of hiring
  - More flexibility (to fire, sub-contract, etc.)
  - No payroll taxes/benefits
  - Attracts disability organizations that can provide other resources (office, phone, computer, copier, meeting space, etc.)
- Be shameless in asking other disability organizations to support you.
  - It is their duty to support disability advocates and many are just waiting to be asked
  - “Nothing about me without me” is NOT just a catchy phrase.
- You can make a big impact with a small amount of money if it is a good idea

# People First of Nebraska, Inc.

Advocacy for and by People with Disabilities

PeopleFirstNebraska@Outlook.com



Nebraskans with disabilities offer the following advice to our friends and neighbors in the community:

**Put me first,**  
Don't be afraid of me **not my disability**  
**Support and advise me, but know that**  
**I make the choices about me**

**Listen to me and respect** I am an adult,  
**my opinion** please treat me like one.

Wait to be asked **Be friendly**

A change in my health may be the  
reason for a change in me

**Don't use the "R" word. Ever.**

**Assume** Don't touch my wheelchair,  
**Ability** service animal, or other assistive  
tools without my permission

I am not a mistake or a burden,

**Invite me along,** I am a person.  
**I'm fun!** My behavior may

**Challenge me, don't** be telling you  
**stereotype me** something I can't

Talk to me, not just the people with me

Remember that everyone has  
bad days **Not all disabilities**

**I'm probably interested in** **are visible**  
**some of the same things you are. Ask!**

Don't be afraid to make a mistake.

No one is perfect!

This poster was developed through a grant from the Nebraska Planning Council on Developmental Disabilities.

Nebraskans with disabilities offer the following  
advice to health care professionals:

**Don't be scared of me** **Talk in words that I can understand**

**Tell me what you are going to do before you do it** I need regular check-ups

**Treat me as you would want to be treated** My Body  
My choice!

**It's my decision, not yours** Sometimes I need my doctor to fill out forms.

**Answer my questions truthfully** Please don't get mad at me or charge me extra.

**Talk with ME not my staff** **Respect my right to privacy**

**Listen to Me and Respect Me** **Help me learn about my health**

**Sometimes I need a break,** I am not a child,  
I am an **adult** **so I can make better decisions**

**please let me rest when I ask you to** I can't climb onto your exam table and  
your rooms are too small for my wheelchair

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Nebraskans with disabilities offer the following  
advice to support staff and service providers:

**Don't be scared of me** **Remember this is my home, not yours**

**Give me space** I have the right to say "No" **Teach me, don't do it for me**

**when I ask for it** **Explain things in a way I can understand**

**It's my decision, not yours** **Listen to me and Respect me**

**Understand that every person has bad days** **I need sick leave and**

**I am an adult; treat me like one** **vacations, just like you**

Call me by my name, not nicknames you think are cute

**I'm the expert about me.** **Don't touch my wheelchair, service animal,**

**Talk with me, not at me** **or other assistive tools without my permission**

**I am a person - not a bed, a program, a number, or a diagnosis**

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## What a Self-Advocate looks like

**Speaks up** Shows up and does what  
they say they will do

Has courage even when they are scared

**Not afraid to disagree** **Learns new skills**

Cares about and is active in their community

**Steps up to advocate without**  
**being asked** **Advocates for others, too**

An everyday person with a little extra courage

**ME!** **Speaks truth to power**  
**Mentors new self-advocates**

## How to support a Self-Advocate

**Start teaching youth** **Create a safe place where**  
**about self-advocacy early** **people can disagree**

Recognize that I am the expert about me

**Wait to be asked** **Help me reach out to**  
**new self-advocates**

Pay me for my advocacy services, just like you pay others for their work

**Don't punish me for my opinions or self-advocacy**

**Respect my opinion** **Support and advise me,**  
**but know that I make the choices about me**

**Have self-advocates at the table the**  
**first time and every time** **Put me first,**  
**not my disability**

**Always include a self-advocate as an**  
**expert when disabilities are discussed**

This poster was developed through a grant from the Nebraska Planning Council on Developmental Disabilities.

# Lessons Learned

- Develop transparent financial procedures
  - > Staff DO NOT have access to the bank account
  - > Officer, State Advisor, Support staff, and CPA provide checks and balances between each other
  - > Get your own bank account and FREE Federal EIN  
[https://www.irs.gov/Businesses/Small-Businesses-&Self-Employed/Apply-for-an-Employer-Identification-Number-\(EIN\)-Online](https://www.irs.gov/Businesses/Small-Businesses-&Self-Employed/Apply-for-an-Employer-Identification-Number-(EIN)-Online)
  - > PFN staff can walk you through process on the phone
- Make sure chapters are independent
  - > Not influenced by provider or parent advisors
  - > Members openly nominate, elect their own officers
  - > Members adopt their own by-laws
  - > Members set goals and agenda

# Resources out there...

- Other self-advocacy organizations officers, web sites, on-line resources
  - Heartland Self-Advocacy Resource Network
    - <http://heartlandselfadvocacy.org>
  - People First of Missouri [www.missouripeoplefirst.org](http://www.missouripeoplefirst.org)
  - Self-Advocate Coalition of Kansas [www.sackonline.org](http://www.sackonline.org)
  - People First of West Virginia
    - [www.thearcofwv.org/people-first/home.html](http://www.thearcofwv.org/people-first/home.html)
  - National Gateway to self-determination
    - <http://ngsd.org>
  - National Resource Center for Supported Decision-Making <http://supporteddecisionmaking.org>
  - AT Conference Call System [www.atconference.com/](http://www.atconference.com/)

# People First of Nebraska can offer ...

- Electronic copies of
  - > grant applications
  - > By-laws
  - > Posters and brochure
  - > Staff support job description
  - > Staff support contract and sub-contract
  - > Convention programs, meeting agendas
  - > Recruiting fliers
  - > Financial Management Process
- Fundraising ideas
- Technical Support



# Questions?



**People First of Nebraska, Inc.**

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***"Nothing About Us Without Us!"***

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"People First of Nebraska"

[www.PeopleFirstNebraska.com](http://www.PeopleFirstNebraska.com) (coming soon)