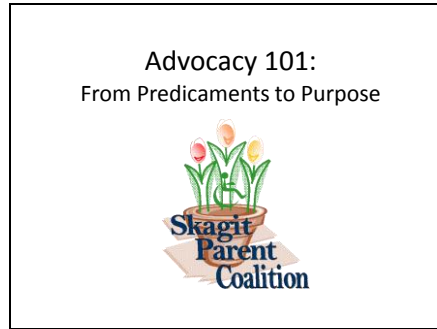


Slide 1



**B10 Advocacy 101: From
Predicaments to Purpose, presented
by Joy
Caldwell, Coordinator, Skagit Parent
Coalition for Developmental
Disabilities**

Slide 2



- Current Coordinator for the Skagit Parent Coalition for dd.
- Small business owner & Consultant
- Software entrepreneur
- Experienced speaker
- 20 years experience as an Office Manager and Administrator for medical and educational facilities.
- Experience as business analyst, project coordinator, technical writer and facilitator.
- Past Chairperson for the Edmonton Down Syndrome Society and an
- Active volunteer within the disability community for many years – both locally and internationally.

Slide 3




Jessica - 11 years old with Down syndrome, cerebral palsy, ADD...

Slide 4

Introduction

- Ever feel frustrated by budget cuts in services for your child or class?!
- Know there must be additional resources and services for a child or family with extraordinary needs but don't know where to find them...?
- Ever want to express your opinion about a government funded program, service or resource but don't know where to start?
- Ever wish you had some help organizing your children's medical or educational information in a way that would communicate more effectively to health care or school professionals about the resources and services they need?



How many parents?
Teachers?
Caregivers?

Slide 5

Objectives for Workshop

We will learn:

1. Practical strategies for turning our predicaments into purpose.
2. How to navigate the complexities of our system.
3. How to be a more effective citizen - as an advocate and voice of change.
4. How to organize school and health records & merge them into a practical plan.

Which one do you want us to focus on today? Why are you here?

Slide 6

Objective 1: Practical strategies for turning our predicaments into purpose.

Identify Need

- What are you frustrated about?
- What is your predicament?

Identify Goal

- What would you like to see happen?
- What is the desired result?

Make a Plan

- How can we accomplish this?
- What steps do we need to take?

Slide 7

Identify Need

- What are you frustrated about?
- What is your predicament?

- Elected Officials from Skagit County need to hear more from Skagit families about services, resources, programs, etc. (They can't represent us if we're not talking...)
- Skagit families affected by developmental disabilities need:
 - More information regarding services, resources, programs
 - More education regarding importance of advocacy

Anyone want to share their need...?

Slide 8

Identify Goal

- What would you like to see happen?
- What is the desired result?

ARC of Skagit/Island with Parent Coalition program.

Slide 9

Make a Plan

- How can we accomplish this?
- What steps do we need to take?

- a. Help others see the need (Clear Communication)
- b. Put a plan in place (Organization)
- c. RFP for Coalition Coordinator (Implementation)

Slide 10

Objective 2: Navigating the System

- Parent or Professional**
 - Parent Coalition, Parent to Parent, & DD County Coordinators available
 - Network with your contacts
- Print Resources**
 - Early Intervention Resource Guide
 - County DD Guide
 - Telephone Book
- Online Resources**
 - SkagitParentCoalition.org
 - SkagitP2P.org
 - InformingFamilies.org
 - ArcWa.org

How do we navigate the complexities of our system to locate and access services and resources available to children and families affected by special health care needs or developmental disabilities?
We find a “Road Map”

Slide 11

Objective 3: Be a more effective citizen - as an advocate and voice of change.

What is Advocacy anyway?

Sounds more like a job for professionals, teachers, maybe a “Lobbyist” ... not me!

Providers are equally important in this process as you can often represent groups of people with similar needs.

Slide 12

Advocate

Add my **Voic**e to the **Deb**ate


Together
we are louder
Together
we are stronger



Slide 13

Effective Advocacy is NOT:

- Angry
 - Demanding my own way
 - Writing nasty letters
 - Making angry phone calls
 - Yelling and screaming
- Passive
 - I'll just sit here and wait for it all to work out
 - No news is good news
 - Que sera sera – whatever will be will be...



Some people get bad reputation – known for being difficult or not there... which are you?

2nd Hospital story – time & place for anger – make sure it counts – directed appropriately.

Jessica - 8 months old very sick in H
•Near deaf – never cried, made much fuss

•Was on strict feeding schedule

•I had been cooped up for days – going to go across to mall w/ husband and daughter for couple hours.

•Left very specific instructions w/nurse on duty re: feeding schedule – bottle ready next to bed


•Came back and when she should have already had 2 bottles, she had none.

•Spoke to staff – very upset. Then went to Pediatrician who took care of it!

Slide 14

Effective Advocacy IS:

1. Knowing your rights and responsibilities.
2. Partnering with others, (recognizing each other's unique role - job description)
3. Being willing to take a stand and "add my voice".
4. Being courteous and careful.
5. Telling a story on behalf of myself or another.



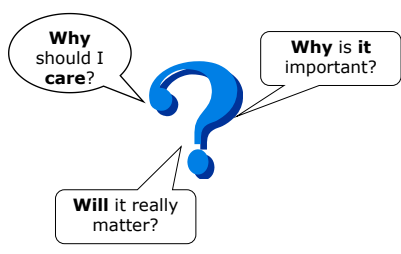
School IEP example
No matter what the setting, the same principles hold.

Slide 15

Different Settings for Advocacy

- At School – IEP's
 - Teachers, Educators, Therapists
- Work – Supported Employment Plans
 - Job Coaches, Assistive Technology, Therapists
- Hospitals/Medical Facilities – Health Plans
 - Doctors, Nurses, Staff
- Home – Aids to Daily Living
 - Care Providers, Support Staff
- Government – Laws & Budgets
 - Affect programs, services & cash flow to ALL of the above & more...

Slide 16



Why should I care??

Slide 17



There are many different pieces that make up the puzzles of our lives. Each one matters. What would you do without one of these? Other areas could/would suffer, right?!

People with disabilities are not without a voice; however, I would dare say that they have to speak up much louder & often have to make a bigger scene to be heard by others who would prefer to overlook them.

In each of these areas, our family members need to know how to speak out for themselves and more often than not, need our help and assistance in speaking out/up for them.

Slide 18



In America, we value Freedom & Choice in all of these areas:

Where we live

Work – How much \$\$ we can make

Go to school

How we get there

Why should it be any different for people with disabilities?

Remember these things that matter to you...?

The Government won't know where & how we want them to spend our tax money on these services unless we tell them...

Slide 19

So how do we let the “funders” know what we need? How do we let them know our opinions about how their decisions are affecting our children and families?

This is what we call advocacy...

Slide 20

Legislative Advocacy is...



***Making Government
Work for You***

Slide 21

So if Legislative Advocacy is “telling the Government” how to make the laws & where I want them to spend our tax \$\$...



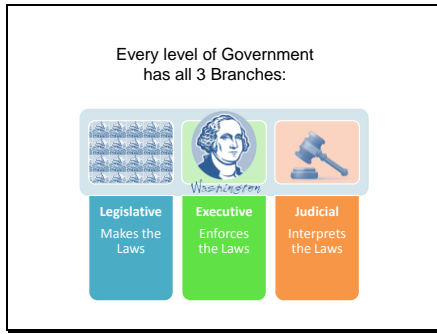
- Who is the ‘government’?
- Who is responsible for what?
- How do I tell them?

Slide 22

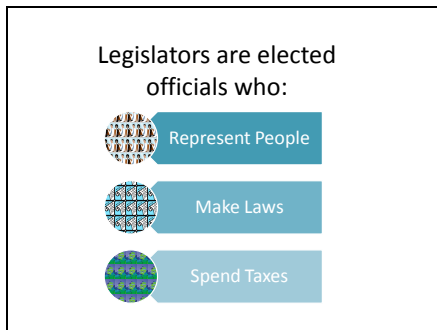


Need to understand the different levels of Government:
CITY OF
MV/BURLINGTON/SW/ANACORTE
S/LACONNER/CONCRETE...?
SKAGIT COUNTY
WASHINGTON STATE
UNITED STATES

Slide 23






Slide 24



Slide 25

Federal Government

Legislative Congress	Executive President	Judiciary Courts
		

Slide 26

Congressional Legislators from Skagit County







- Senator Patty Murray
- Senator Maria Cantwell
- Representative Rick Larsen



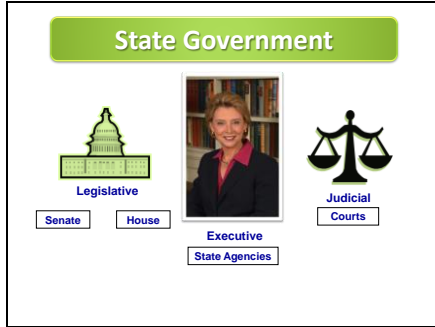
Slide 27

A few Federal Programs that affect our families directly

- Social Security/ SSI/ SSDI
- Medicaid/Medicare
- IDEA (Special Ed)
- Birth to Three (Part C)
- Housing (Section 8)



Slide 28



Slide 29

Each District has:

- 1 Senator
- 2 Representatives

The slide includes three illustrations: a senator in a blue suit gesturing, a photograph of the Washington State Capitol building, and two representatives sitting at a desk.

Slide 30


Skagit & Island County 10th District		
Sen. Mary Margaret Haugen (D)	Rep. Norma Smith (R)	Rep. Barbara Bailey (R)
Skagit & Snohomish County 39th District		
Senator Vail Stevens (R)	Rep. Dan Kristiansen (R)	Rep. Kirk Pearson (R)
Skagit and Whatcom County 40th District		
Senator Kevin Ranker (D)	Rep. Dan Quall (D)	Rep. Jeff Morris (D)

Slide 31

Some of the State Services that affect our families

(*Receive Federal matching dollars)


- Programs of the Division of Developmental Disabilities
- Special Education*
- Medicaid*
- Transportation*
- Division of Vocational Rehabilitation*




Slide 32

Local Governments


Skagit County



Rob Wicks
County Executive




Bill Logg
Commissioners - Legislative



Ken Demistatuk
County Executive

County Executive
Commissioners - Legislative
Courts

City of Mount Vernon



Bud Norris
Mayor - Executive

City Councilors - Legislative
Courts

Slide 33

Local Services

- Public transportation
- Police & Fire
- Energy Assistance
- Parks & Recreation
- Municipal Planning



Slide 34

**Biggest Issue Facing
All Levels of Government**

MONEY \$\$\$

- Deficit
- Economy/Depression
- Bailouts
- Cuts and/or increase revenue
- Tax structure




Slide 35

ABC's of Advocacy

"A" is for ACTION
Add your voice to the debate.

- Make a phone call*
*Less than 5 minutes
- Write a letter
*Less than 5 minutes if you use a web-site & form letters.
- Have a Visit in person
(in Olympia or District Office)
*Legislative appointments usually run no more than 15 minutes



Applies to all settings: Professionals, schools, legislators, Dr's, etc...

Slide 36

WA Legislative Hotline




1-800-562-6000

ONE phone call: Leave messages for:
3 Legislators
The Governor

Slide 37


Hotline Tips

- Write down notes in advance
- Identify the issue you are calling about
- State your position
- Keep it simple and brief



Slide 38

"B" is for Believe in yourself as the Professional Parent/Educator!



Present yourself as a professional.

- Dress "professionally", appropriate for event.
- Be prepared whether in person, writing or on telephone.
 - Know the issue.
 - Have paperwork/reports with you, along with a notebook or pen.

Know your role & be confident.

- You are your child's "expert". You know him/her better than anyone else.
- Bring someone with you as support.

Tell your story - No one can argue with it.

(Safer to be "overdressed" & easier to dress down" than vice versa) First impressions do matter – only because we're "people"... Maybe I do "try harder" only because I don't have the letters behind my name. Either way, it seems to work best for me...

Slide 39



Slide 40

**"C" is for Communicate
Clearly & Courteously**

A clear and simple message says:

- What is important to you
- How it affects your life
- What you want the legislator, professional, teacher or Dr. to do.

A courteous message:

- Builds Bridges
- Is Appreciative



Tell your story, have one or two things you would like them to work on.

Slide 41



YOU CAN MAKE A DIFFERENCE!!

Jessica – I read her chart daily! Took it on myself to become the expert on Jessica. Empowering - turned down thyroid scan.

Slide 42




Slide 43

Letter Writing Tips

- State your name, address and phone number
- Note that you are a constituent
- Be timely
- Neatly handwritten is good
- Personalize: Tell *your* story
- Stick to key points; keep it brief: one page
- Be clear about what you would like your legislator to do
- Mention that you are part of a group
- Ask them to contact you for more info, a response & follow up!
- Thank them.

*Issues with mail at Federal Level due to bio weapons precautions (e-mail better)
ARC of WA has great links directly to all Legislators at State & Federal levels.
Or you can go to house.gov or senate.gov – find Rep or Senator & send message directly from web-site as well.



Slide 44

Get involved:

Go to Olympia during Session

- Learn how the system works
- Learn more about the Issues
- Meet your Legislators



In Your Community

- Attend Town Meetings
- Call in to Radio Shows
- Write Letters to the Editor
- Talk to your Neighbors



Slide 45

Join or Attend Local Government Committee Meeting

- Regional DDD Advisory Committees
- County DD meetings
- County Transportation Committees
- School Board Meetings
- City or County Council Meetings



Slide 46

Connect with Others



- Parent Coalition Meetings
- Parent to Parent Groups
- Advocacy Groups
- People First
- PTO Meetings
- Work Groups/Parties

Slide 47

Attend Legislator's Forums & Receptions

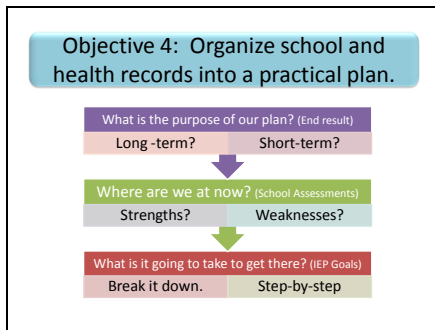
SAVE THE DATE
 Date: **Wednesday, October 6, 2010**
 Time: **5:30 - 7:30 pm**
 Location: **Shagit Valley College Campus** *More information to follow

Annual Legislative Reception



Meet your Legislators
 Educate Legislators on the Issues
 Hear Legislators' Perspectives
 Connect with other Families

Slide 48



This is similar to the steps we discussed earlier. We kind of have to think backwards. What is the purpose of our plan? What do we want the end result to look like? Then we break it down step by step. What's it going to take to get there?


Slide 49

One tool to help you with a one-page summary for medical & education history → ezMedic software



The image shows a collage of items related to the ezMedic software. On the left is a box for 'ezMedic Medical ID Card'. In the center is a screenshot of the software's 'PERSONAL IDENTIFICATION' page, which includes fields for name, phone, and identifying features. To the right is a physical medical ID card. In the foreground, there is a soccer ball with the text 'S10 family' on it.

Slide 50



The image is a screenshot of a medical history summary page. It contains various sections such as 'Patient Information', 'Medical History', 'Physical Examination', and 'Laboratory Studies'. A small photograph of a person is visible in the middle of the page.

Slide 51

Master School Plan

2 Purposes of the “master school plan”:

1. Use as a basis for the IEP. All IEP goals need to be evaluated against the “master plan”.
Will they help us achieve a long-term goal?
2. Advocacy Tool for better systems & services.
(You have clear picture of where you want to go & how system of services can get you there.)

Slide 52

Overall Goals for Jessica

- Long-term/Life-time – Jessica will be a responsible young lady, working and living in our local community as independently as possible with appropriate supports and accommodations, enabling her success. She will be given every opportunity to make independent choices and decisions for herself, for her present and her future.
- Short-term: Give Jessica as many opportunities as possible now, within her range of abilities, in order for her to gain the necessary skills for responsible and independent choices. As Jessica proves herself, the level of responsibility and accountability will increase with the level of choices given.

Slide 53

Cognitive Skills – Academics: Reading, Writing, Math, Science, Social Studies

- Goal – Understand value of money. Make purchases by herself. (Name & sort money. Understand individual values of coins/bills. Count money – Use debit/gift card.(?)
- Goal – Understand basic time concepts – daily schedule – what happens at what time?
- Goal – Understand time concepts based on clock/calendar – minute, hour, day, week, month, year...
- Goal – Be able to write &/or tell a logical "short story" – sequence of events
- Goal – Understand differences/similarities between people, plants & animals. Relationship between earth, sun, moon, stars. Concepts of units being part of the whole and her place in our neighborhood, community, city, county, state, country, continent, hemisphere, planet earth.

Slide 54

Social Skills & Communication (Speech & OT Therapy)
** Involve technology as much as is appropriate given real world scenarios*

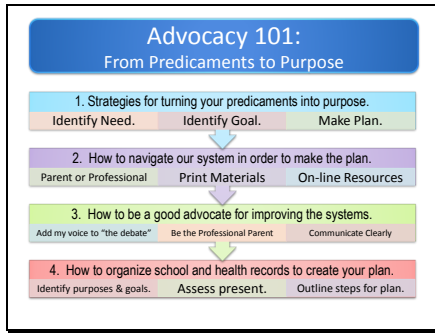
- Goal – Listen /Watch iPod/stereo/video player with headphones. (Doesn't like headbands or anything on her head/ears.)
- Goal – Know address & home telephone.
- Goal – Use a telephone/cell phone independently. (Voice & text)
- Goal – Basic computer/social networking skills for communication, music, entertainment.

Slide 55

Independent Mobility (PT)

- Goal – Ride public transportation with little to no assistance.
- Goal – Ride a bike independently.
- Goal – Drive small electric vehicle at low speed. (ie: golf cart)

Slide 56




Hopefully you will remember what we learned today:

Slide 57

Thank You for Coming!

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."
Margaret Mead



Joy Caldwell
Coordinator