LIVE WITH SPINA BIFIDA IN SLOVAKIA



WHAT´S THE PURPOSE OF IT 2013

Sofia

SB a H SLOVENSKÁ SPOLOČNOSŤ PRE SPINA BIFIDA A HYDROCEFALUS

Everything start with birth of Dominik



- It was recommended to let him die
- No literature, no knowledge, no experience
- No Future

12 years of waiting for death







Shadow of death

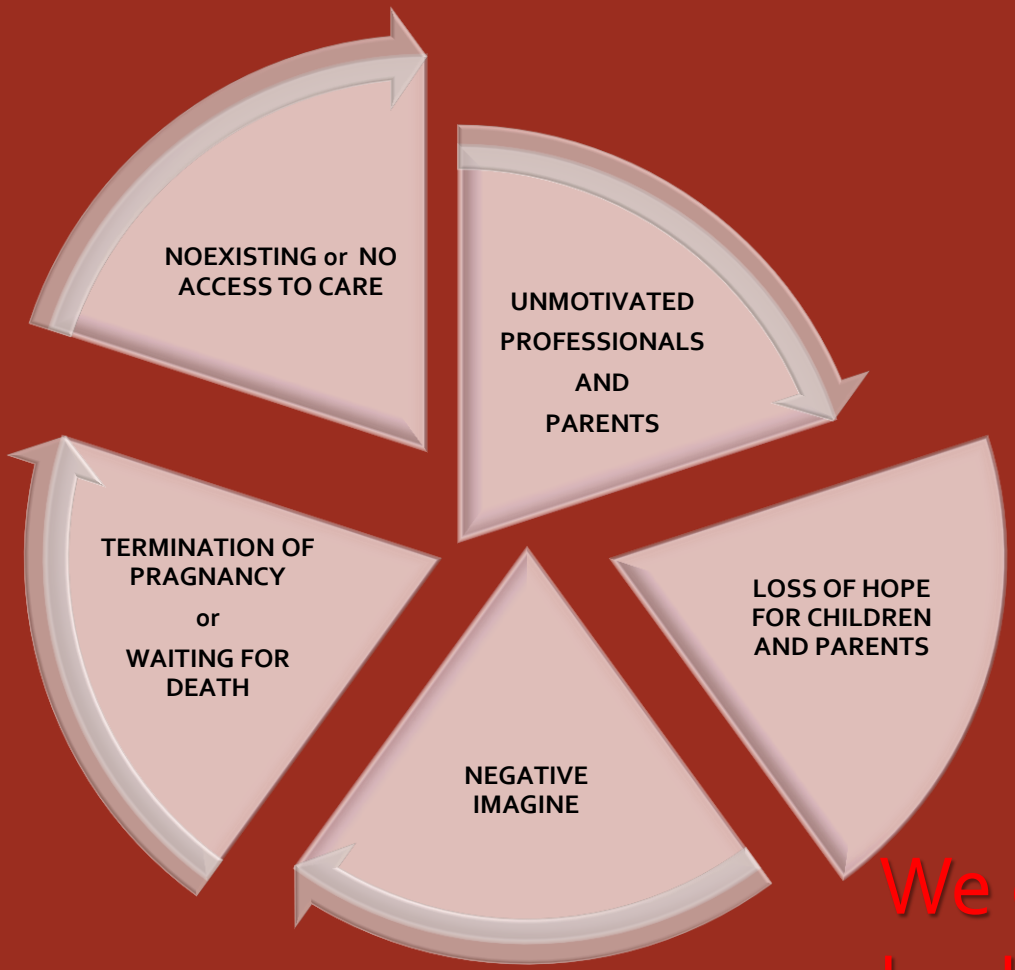
Effects for the Future

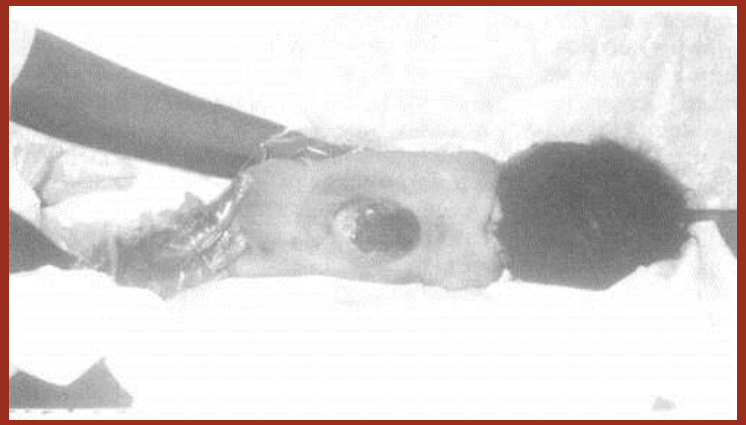
Frustration

Limited Education Access

Limited social relations

~~No surgery intervention~~





No face black/white picture offered by literature, some professionals

We choose to broken this cycle

FOUNDATION OF ASSOSIATION

ALL MAY BE DIFFERENT

Many things depends from what you want to see.

Ask good questions:

- Why?
- What (?) s the purpose of it?
- Whom for ?
- How?

Whatever change always start with small things – positive picture and enthusiastic group



Picture This…

PROFESSIONALS INVOLVED

MOTIVATED PARENTS

THE CARE IS ACCESSIBLE

HOPE

POSITIVE OUTCOME– realistic image









SB a H
SLOVENSKÁ SPOLOČNOSŤ PRE SPINA BIFIDA A HYDROCEFALUS



« WE ARE HERE – TO LIVE! »

Slovak association for spina bifida and hydrocephalus

NGO - association mostly of parents, adult people with SB,H or another dissabilities

We started in April 2004

Small organisation - 200 members

Big group of voluntaries - more than 200 people of all ages

Majority of work is provided voluntary

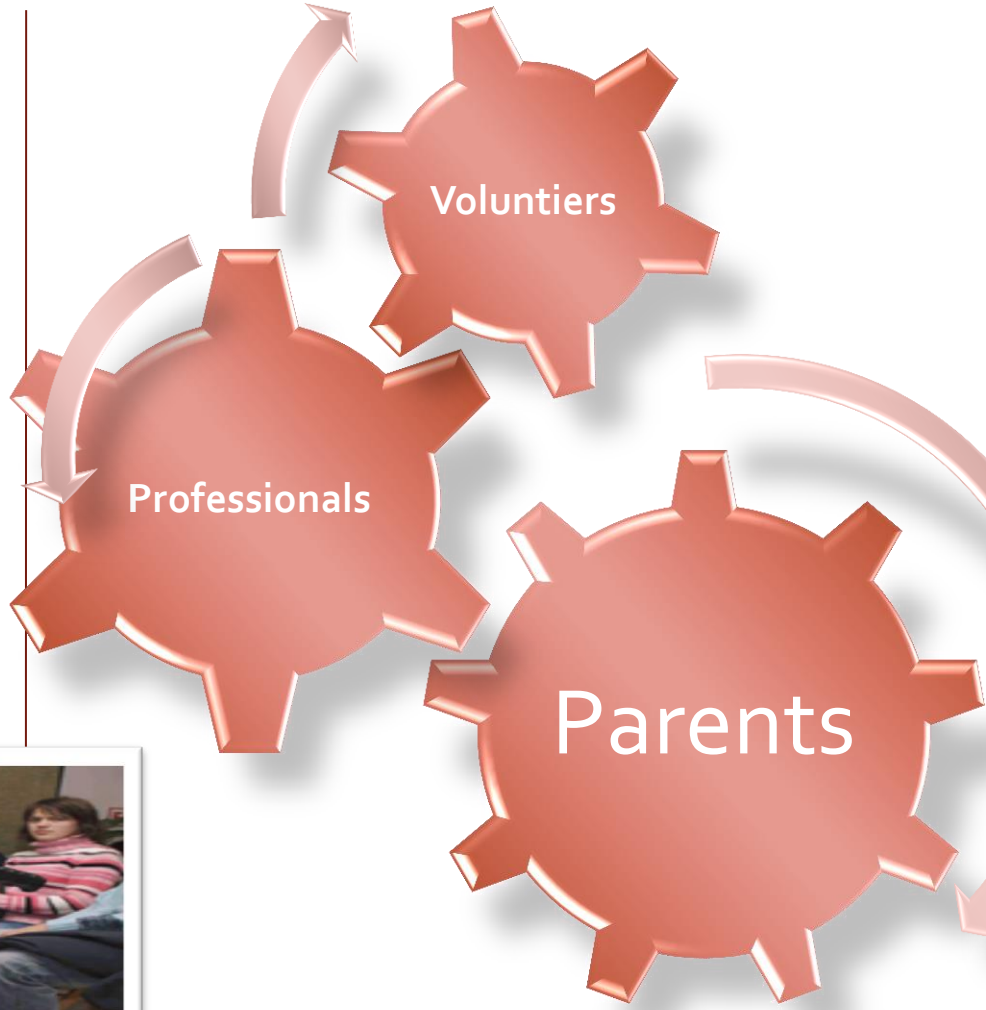
Cooperation with Inernational Federation for SBH and other foreign countries

1. Knowledge network
2. We have it only as we will do it
3. Whom for?
4. How to get people involved ?

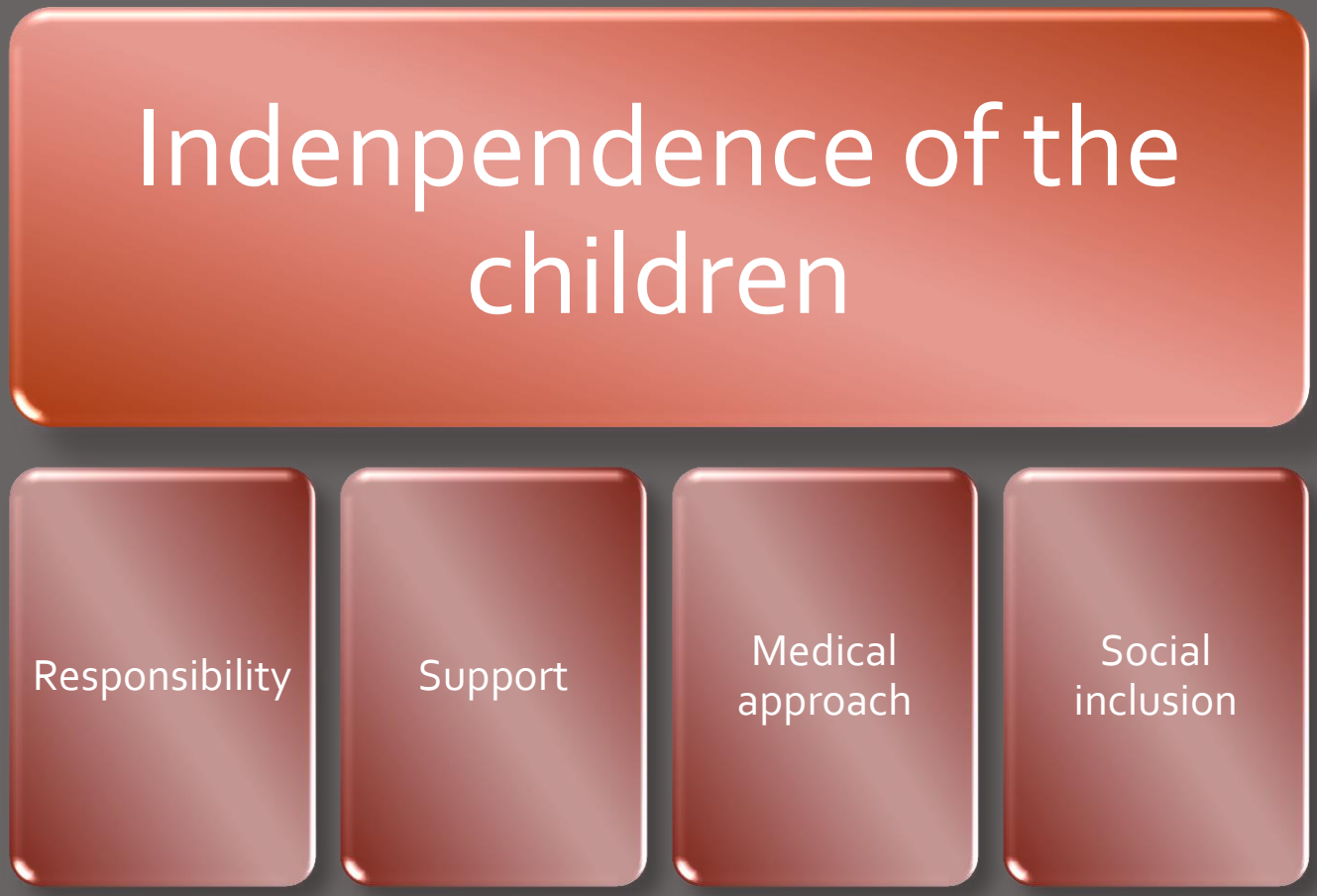
April 2004 and after it

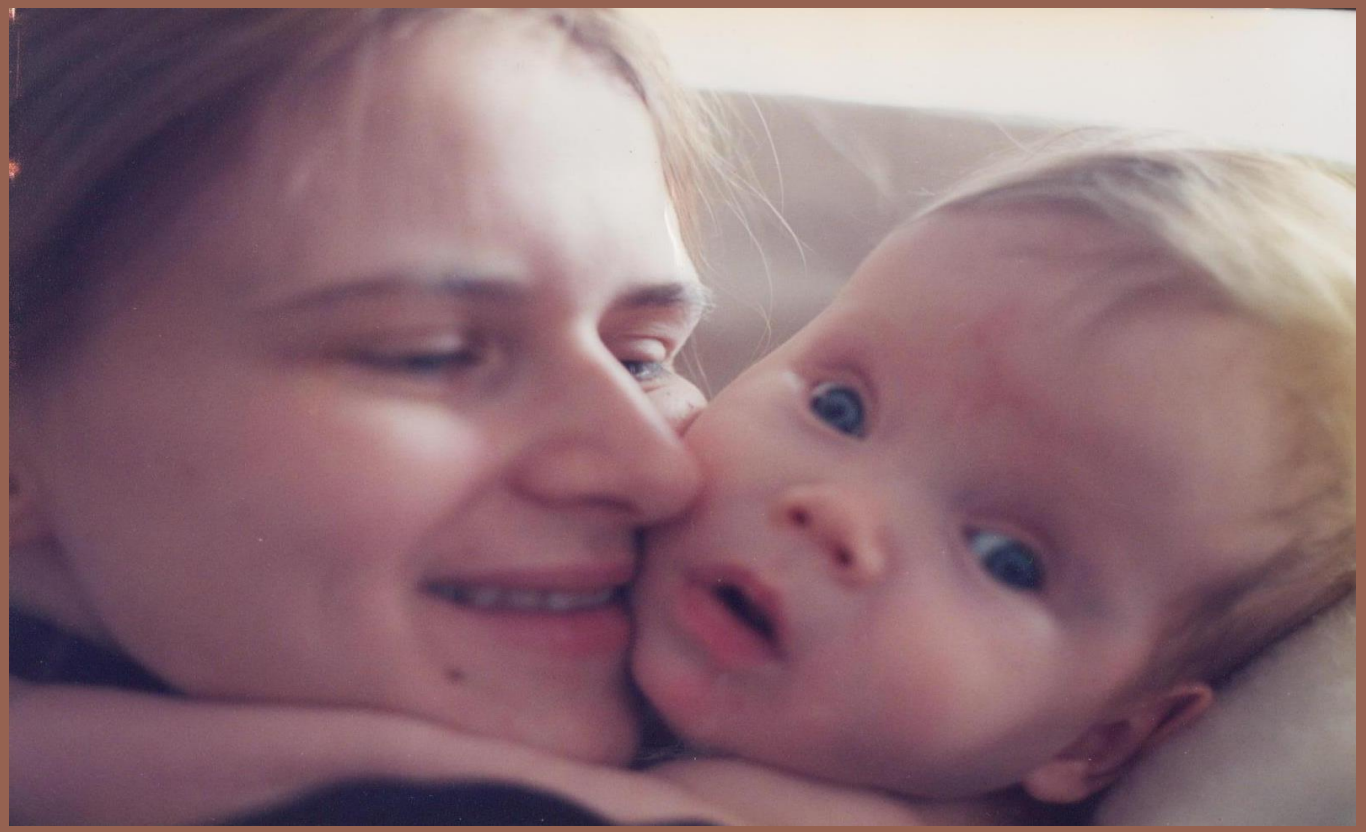
1. Small Group of Parents starts to understand why change and build up knowledge network is important
2. Many professionals and voluntiers became involved
3. Positive examples are exposed
4. Goal: to help actual children to be as much as possible to be indenpendent





Multidisciplinary approach in our view





EARLY INTERVENTION

Training for parents of children from birth to 3 years old

Focus was done for very young parents with children with SB.

Organizing meeting all around the country with goal to involve and spread knowledge.

The parents starts to be EXPERTS for their children







Practical help for everyday life

-To have/don´t have **wheelchair** - for the child as does or doesn´t have **wings**.

- A child with no walking = no inclusion to peers

- Stabilization of children brought different view, experience and many preventions

- Inclusion children in to the children gardens and schools

- Catateriśation as daily life of style



Mix It Up!

All leveles have to be **balanced**:

-Medical treatments

-Social inclusion

- Educational development

-Personal skills and hobbies

- Family support

If there is focus only for medical treatment exclusively these alone do not solve future personal development and inclusion.

In some periods of life are some topics more urgent to others but icomplexity is always necessary to have in front of eyes.

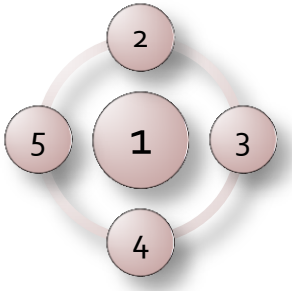








Find Your Style



No General recepts exists and never will be invented.

Everybody is in unique situation and in this situation is possible to build up trustworthy motivating atmosphere.







PERSONAL CHARACTER IS MORE IMPORTANT TO *PERFECT* HEALTH CONDITIONS



WE ARE DOING THE PATH TOGETHER

At Conclusions

-No effective and early intervention system in Slovakia.

-No support of our work from state institution

-Lack of information, leaflets, brochures, books

-Lack of multidisciplinary teams of professionals

-No early and effective help for families with children with a disability:

= social exclusion of the families
= high risk of social exclusion for children in the future
= high risk of dependance on family carers
= high risk of dependance on family carers

BUT LITTLE LIGHT BRINGS HOPE IN DARKNESS

Prevention

Prevention is much cheaper and effective – its influence concrete idenpendent life and future adult life



Indenpendence

= It is complex life skills and abilities – life style:
I AM ABLE TO DO MANY THINGS ALONE



- GOAL:

In the future its able for regular work and to build up regular social relationships

To do list

1. To manage regular meetings to share knowledge
2. Cooperation with professionals not explicitelly Doctors. Build up and maintain effective network.
3. Involve voluntaries
4. To find person who will coordinate all activities
5. Don´t worry to make small steps

-Management of good quality wheelchair, exchange some tools

6. Showing for the positive examples



7. Invest into the families with small children: show them how it could be and involve them into the positive cycle (Terezia may come for some lesson)
8. To menage a lot of funny and sports activities

Thank you

Our daily experience build up knowledge

Our network is growing continually

Our work create confident and trust

The positive picture start to be reality





What ?

