

1 ☐ **Motivating Parents of Hearing Impaired Children**
DHICE 2005, London

2 ☐ **Topics**

- Story of my son
- Early diagnostics, NHS
- Centres of Early Intervention
- Special Education Centres
- Education choice
- CI programme
- SUKI, Broken Silence (project for children with complex needs)

3 ☐ **Story of my son – Why I am here?**

- Mirek lost hearing at age of 7 after meningitis
- Shock of learning about diagnose
- Decided for CI
- Problems:
 - no CI Programme in CR, no finance sources, no specialists experienced about CI
 - Implanted at 8 years of age in Germany
 -WE WON!

4 ☐ **Mirek - CI user**

5 ☐ **Early diagnostics**

- Paediatrician's examination x NHS

role of paediatricians:

- educate specialists and parents
- develop educational materials

NHS:

- **US** reports: 37 of the 50 states have implemented universal NHS
- **Europe**: approx. 20% of all newborns are screened
- **CR (some countries of Eastern Europe)**:
NHS is only in big hospitals and in some regions and mostly in risky infants

6 ☐ **Early diagnostics**

Goal of early diagnostics for the parents:

- Early possibility for hearing aids/CI
- Early start with therapies
- Early establishment of communication system between deaf child and parents (Total communication, Bilingual communication, Sign Language, Oral)

- Early Intervention Centres help

7 ☐ Centres of Early Intervention

- For HI children from the birth to 7 years of age
- Goal: early and intensive support for families with HI children, cooperation and advice
- Employees: special pedagogy consultants
- Centres around whole CR, free of charge for families (for most services)
- Services:
 - emotional support, dealing with post-diagnosis shock or difficulties of accepting a deaf child
 - help with continuing diagnostics (psychological, special pedagogy, speech therapy diagnostics and care, videoanalysis)
 - connection families with local specialists

8 ☐ Centres of Early Intervention

Services...

- individual therapies and care for children
- group therapies for children and parents

aim of the group therapies:

- development of communication between child and the parents
- better co-operation of children in the group
- experience share between the parents themselves

9 ☐ Centres of Early Intervention

Services...

- lectures about specific topics for parents (seminars and workshops)
- providing social services
- weekend's and summer camps
- pre-school education advice
- Sign Language courses
- special programmes for pregnant HI mothers and care after delivery (translating services)
- rental and sale of literature about deafness, special toys and equipment, computer programmes

10 ☐ Special Education Centres

- For HI children from 3 – 18 years of age
- Around whole CR
- Mostly attached to special pre-schools and schools for HI
- Employees: special pedagogue, teacher of deaf, psychologist, social worker..
- Services for:
 - parents
 - children
 - teachers in mainstream schools

11 ☐ Special Education Centres

- Services for parents:
 - Parent guidance of different specialists needed
 - Help with communication with the child

- Social counseling, low services
- In case of financial problems advice to parents about non profit organizations
- Finding a best choice of education of HI child (contacts of suitable and local schools), integration
- Psychological and special education diagnostics and evaluation, psychotherapy for parents if needed
- Rent and sale of special education literature and equipment
- Sign Language classes for parents

12 ☐ Special Education Centres

- Services for children:
 - Individual therapies and special education plan
 - Speech therapy care, finding local specialists
 - Short term diagnostic visits at schools which could be suitable for education of individual HI child
 - Integration possibility counselling

13 ☐ Special Education Centres

Services for mainstream schools if HI child is integrated:

- Evaluation of every HI child
- Support of integration of HI child
- If needed care of financial support of HI child
- Special advice to teachers in mainstream schools
- Create individual education programme for integrated child
- Information of equipment needed for child
- Rent of FM systems and other equipment

14 ☐ Education of HI children in CR

- Special pre-schools and schools for HI children (16):
 - from 6 – 15 years of age
 - different communication system used
 - individual education plans
 - limited number of children in the class
 - special therapies included
- X
- mainstream schools integration (with or without learning support assistant)
- Continuing education for teenagers and adults..

15 ☐ Education of HI children in CR

16 ☐ Cochlear Implant Programme in CR

- Programme started 1993
- 2 CI centres in Prague:
 - children x adults
 - 210 children, 90 adults

17 ☐ Cochlear Implant Programme in CR

- specific diagnostics (medical x non-medical) and selection of candidates:
 - *new criteria trends (not all of them in CR yet)*
- advice and support of parents and good information about whole CI process and their role

- rehabilitation before and after CI
- education support and advice

18  **Parental Expectations of Benefit from CI, N= 196**

19  **SUKI – Association of CI users**

- Association of CI users
- Established 1994 and number of parents of CI children is increasing every year

- Number of members:
 - now 134

- Finance:
 - contribution by members
 - donations and gifts
 - grants
 - occasional incomes from events organized by SUKI


20  **SUKI**


- Association of CI users
- Main aim:
 - to represent the interests of CI users and their families
 - to associate the parents of children with CI, adults with CI and other people interested in this field


21  **SUKI**

- Association of CI users
- Services:
 - **regular meetings for families of HI children** – CI candidates and users - weekends and week lasting
 - **programme of those meetings:**
 - education lectures for parents
 - possibility of experiences exchange in everyday care
 - information about technical innovations
 - every day rehabilitation for CI children
 - entertainment programme and trips for families

22  **SUKI meetings**

23  **SUKI - meetings**

24  **SUKI - meetings**

25  **SUKI - meetings**

- 26 ☐ SUKI meeting – therapies with pets
- 27 ☐ Broken Silence Foundation
- **Main objectives:**
 - financial support for CI children
 - support of CI-programme in CR, international co-operation
 - financial support of education of CI specialists (courses, conferences, Sign Language lessons..)
 - project for complex needs children – CI candidates from children homes and institutions
- 28 ☐ Broken Silence Foundation
- Project for complex needs children – CI candidates from children homes and institutions
- 29 ☐ Broken Silence Foundation
- project steps:
 - seek for CI candidates with complex needs in children homes
 - diagnostics
 - rehab support before and after CI
 - finding parents for adoption of child with complex needs
 - financial support of those children and adoptive parents
 - education of local specialists from children homes
- 30 📺 Broken Silence Foundation –
video of 3,5 years old boy from children’s home, 5 months in new family, will receive CI soon
- 31 ☐ Wishes of HI children parents
- universal NHS through out the CR
 - modernize hearing aids services
 - relaxation of CI criteria (very young children, older children, residual hearing, complex needs children, deaf children of deaf parents, children without parents)
 - better support of children with complex needs
- 32 ☐ Conclusions
- Early diagnostics importance
 - Early therapies start
 - Good choice of communication method and suitable education
- GOAL!
- Parental support in whole their way of life with their hearing impaired child and make them happy...
- 33 ☐ Thank you very much for your listening