

Protocol
2nd meeting
Budapest 26-28 02 2014

Participants:

Inkendaal (BE) – Domonique Fragnant, Greit Jacobs, Nicolas Steppe, Céline Opsomer, Beáta Tóth

Percy Hedly (UK) – Lynda Show, Sara Kay

NICE (UK) – Beáta Szeszák, Erika Sisák, Katalin Gönczy

Phoenix (DE) – Fredrike Hertwig, Silke Klemm, Gabriele Sosic

Joriel Skolan (SE) – Kim Perneberg, Charlotte Karlsson, Katalin Mazzag-Aström

ITA (AT) – Bettina Tautcher

Pető Institute (HU) – Host – Éva Feketéné Szabó, Zsófia Nádasi, Eszter Daróczy, Conductors from the school, conductors from the kindergarten

Programme carried out:

Wednesday, 26 February 2014

Time	Programme, activity	Participants
8.30 – 10.30	Visiting the Institute – Kútvölgyi út	Inkendaal, NICE Percy Hedly Joriel
11.00 – 11.30	Opening the meeting, discussing the schedule, introduction of new participants	All
11.30 – 12.30	Introducing measurements and documentation system (we could not do it in Vienna)	NICE and ITA
12.30 – 14.00	Lunch break Travelling to Villányi út	
14.00 – 15.00	Discussion on the results of trying the different classification systems – GMFCS, MACS and CFCS	Percey Hedley, Phoenix, Pető, Inkendaal, NICE, Joriel
15.00 – 16.00	Visiting the School of the Pető Institute	Inkendaal, Percy Hedly, NICE, Joriel, Phoenix

Experience of the first day:

- The programme was followed according to the plan.
- We discussed the results of all the classifications. We discussed that we might not find “all in one” measurements
- We prepared the next day

Thursday, 27 February 2014

Time	Programme, activity	Participants
9.00 – 10.00	Useful, easy to handle table on age equivalent cognitive classification according to age development Discussion	Joriel and Phoenix
10.00 – 11.00	Introduction of PEDI	Percy Hedly
11.00 – 11.30	Coffee break	
11.30 – 12.30	Introducing QOL system for measuring the Quality of life	Inkendaal
12.30 – 14.00	Lunch break	
14.00 – 15.00	Introducing FIM system for measuring the participation in life management-self care Introduction of WeeFIM	Pető (Mr Miklós Fehér MD in rehabilitation) Percy Hedly
15.00 – 16.00	Discussion on QOL and FIM	All

Experience of the day:

- Joriel indicated that in Sweden cognitive function's, intellectual level can not be measured by the school it is done by specialists
- The situation is the same in Germany and we realised it is the same in every participant's country

Decision: We will not deal with the intellectual development measurement as this is licenced to psychologist in all countries.

- We learnt about QOL, FIM and WeeFIM as a possible measurement of quality of life
- Further study other tests for measuring how CP people feel about their life
- We continuing collecting more articles and information on measurements concerning the development of children with CP – standardised/approved tests will be needed

Friday, 28 February 2014

9.00 – 10.00	Introduction GAS Discussion on QOL and FIM and GAS	Pető – Dr Miklós Fehér MD in rehabilitation) All
10.00 – 11.00	Summary of the tests presented during this meeting	ITA
11.00 – 11.30	Coffee break	
11.30 – 13.00	Discussion on the next steps	All
13.00	Closing the meeting	

Experience of the day:

- We further search for tests for measuring the quality of life
- Further describe tests and target groups – see what tests are used in institutions using other development/rehabilitation methods on national level

We also discussed our common webwork possibilities: Joriel recommended to use e-Twinning – further check will be done.

Homework:

- Collecting literature on national level
- Introduction of measurements:

Percy Hedly: GMFM, COPM

Phoenix: ICF, DTVP2

NICE: ICF adaptation for cond ed.

Inkendaal: EDACS, creating and filling a chart for classifications and levels – experience and benefit

Joriel: NAS (Nordic assessment score)

Pető: Summary of the evaluation sheet/feedback; Paneuropean project “Sparkling” – KIDSCREEN