

INSPIRALSPITAL
 UNIVERSITÄT WÜRZBURG
 INSTITUT FÜR NEUROLOGIE UND PSYCHIATRIE

Le passage de l'enfance à l'âge adulte chez la personne handicapée

Du point de vue du pédiatre

Sebastian Grunt
 Abteilung Neuropädiatrie

Exemple

Life Time Events durant l'adolescence

L'adolescence de la personne handicapée

Handicap	Prise en charge par tiers
Communication	Dating
Incontinence	Profession
Cognition	Habitat
Structures corporelles	Loisirs

Transition des systèmes de santé

“ Purposeful movement of adolescents and young adults with chronic conditions from child-centered to adult-centered care”

Blum et al 1993 (J Adolesc Health)

Où diriger nos patients ?

„Infantilisation“

A qui ?
 Comment ?
 Quand ?

Dépendance Difficulté de transmission

Différences entre les systèmes de santé

	Pédiatrie	Médecine pour adultes
Mandant	Parents	Patient
Relation	„tu“	„vous“
Coordinateur	Pédiatre	Médecin de famille
Objectif	Développement	Stabilité
Organisation	Pluridisciplinaire	Spécialistes divers
Contrôles	réguliers	Selon besoins
Financement	AI	Assurance maladie
Maladies	rare	fréquentes
Accès	+/- facile	+ difficile

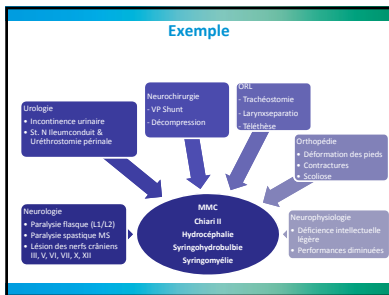
„Transmission des connaissances“

Pédiatre Médecin de famille

D'où à où

- Diagnostic - conséquences
- Développement - vieillissement
- Options de prise en charge – faisabilité
- Connaissances spécifiques
- Situations d'urgence
- Éthique
- Responsabilité
- Adresses

Exemple : Myelomeningocèle



- ### Fonctionnement
- Moteur:** chaise roulante, chaise roulante électrique, mobilité autonome
 - Autonomie:** a besoin d'aide
 - Continence:** incontinence mixte
 - Communication:** amplificateur vocal
 - Cognitif:** handicap mental léger, performances réduites

- ### Questions
- Sexualité & partenariat ?
 - Psychisme ? Acceptation de la maladie ?
 - Visions d'avenir & profession ?
 - Possibilités d'hébergement

Work Participation in young adults with SB

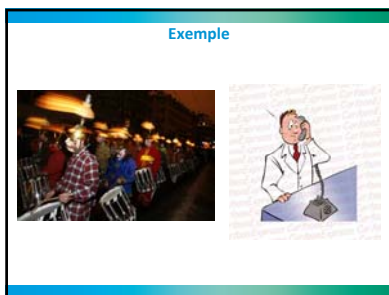
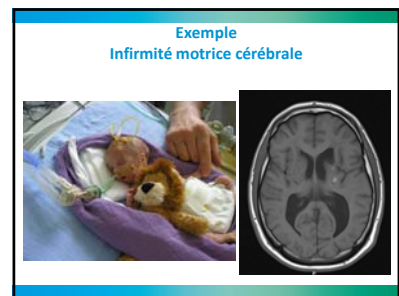
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Male Gender	4.41 (1.94–10.03)	6.17 (2.24–16.97)
Special Education	0.12 (0.04–0.38)	0.18 (0.04–0.76)
Lower Education	0.39 (0.15–1.03)	0.37 (0.12–1.15)
SB Occulta	2.70 (1.01–7.19)	NS
>L2	0.17 (0.06–0.50)	NS
L3-L5	0.48 (0.18–1.28)	NS
No Hydrocephalus	4.20 (1.87–9.47)	NS
IQ>85	2.40 (1.13–5.08)	NS
Incontinence (Urine/Faeces)	1.96 (0.94–4.00)	2.48 (0.91–6.76)
Self Care Independence	7.46 (2.14–25.98)	6.44 (1.22–34.08)
Walking	4.19 (1.86–9.42)	NS

Van Mechelen et al. 2008 DMCN

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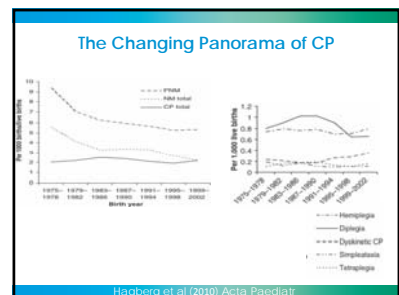


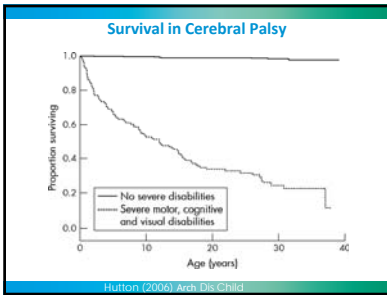
2006 Bax et al

....group of permanent disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.

....accompanied by disturbances of sensation, perception, cognition, communication, behaviour, by epilepsy and by secondary musculoskeletal problems.

Rosenbaum et al. (2007) Dev Med Child Neurol



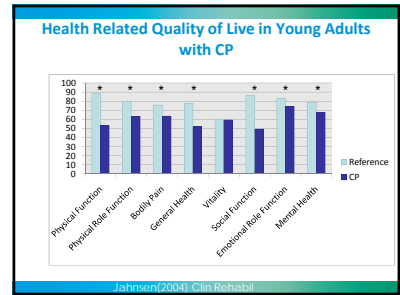


Predicting risk of mortality for cerebral palsy

Effect	Odds Ratio	95% CI
Age (y)		
4-7	0.89	0.76 - 1.03
8-14	0.95	0.84 - 1.07
15-30	1.00	0.995-1.012
Each Year > 30	1.004	
Feeding Tube	2.34	2.00 - 2.74
Mobility		
Low	2.59	2.23-3.01
Intermediate	1.58	1.38-1.82
High	1.00	

n=59653 person-years, 2285 deaths

Strauss et al (2007) Developmental Med Child Neurol



Life Time Costs of CP in Denmark (in Euro)

Cost Component	Men	Women
Health Care Costs Total	66 155	65258
Hospital Costs	51 968	49 921
Primary Health Care Costs	7 182	8 269
Pharmaceutical Costs	7005	7 068
Productivity Costs	332 973	261 597
Social Costs Total	462 578	470 386
Specialized Child Care	219 970	222 026
Specialized Education	70 330	71 069
Other Social Costs in Child Age	63 658	64 147
Day Activities for ADults	21 743	22 605
Housing	78 681	81 998
Other Social Costs for ADults	8 196	8 541
Total Life Time Costs	861 706	797 241

Kruse(2008) Arch Dis Child

