Promoting development of children with chronic complex conditions – challenges and solutions

Social Pediatric Centers (SPZ) in Germany

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Disclosure – Conflict of interest

- Head of the Working Group for Quality in Social Pediatric Care of DGSPJ
- Member of the Scientific Advisory Board of „Central Krankenversicherung“ (Generali Group)
- Financial support for a study on autoantibodies in children with epilepsies by Novartis
- Further scientific support:

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BZgA Bundeszentrale für gesundheitliche Aufklärung

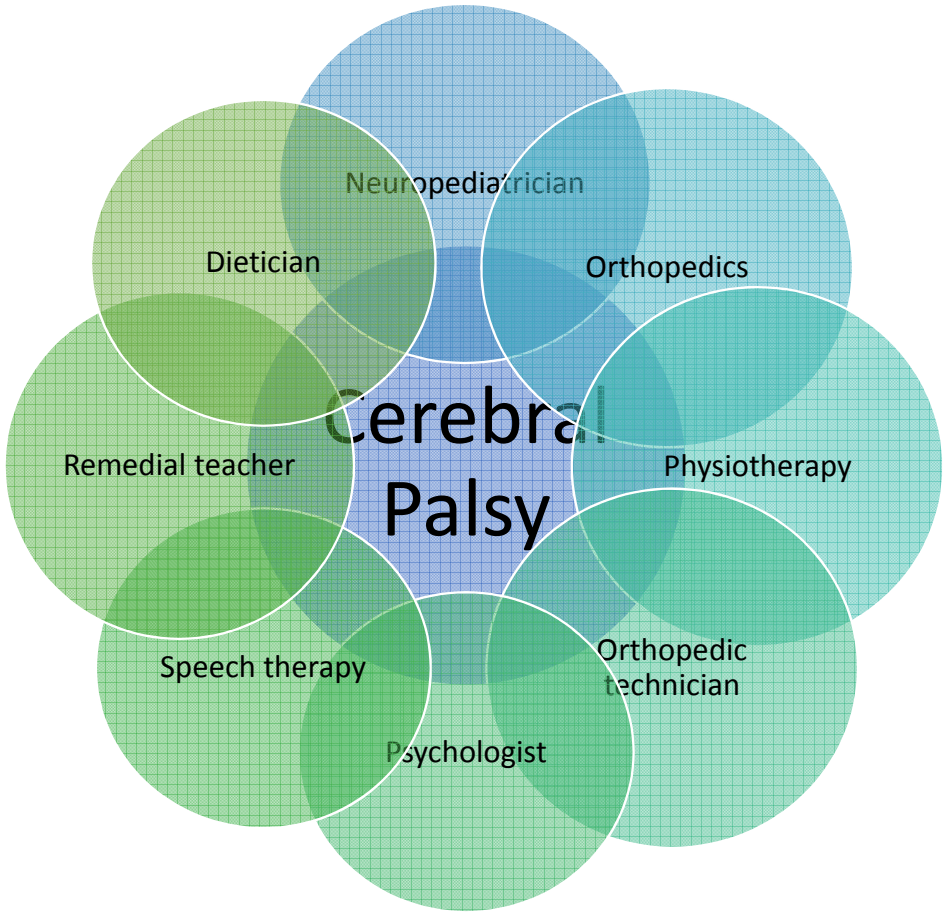
EKFS ELSE KRÖNER-FRESENIUS-STIFTUNG

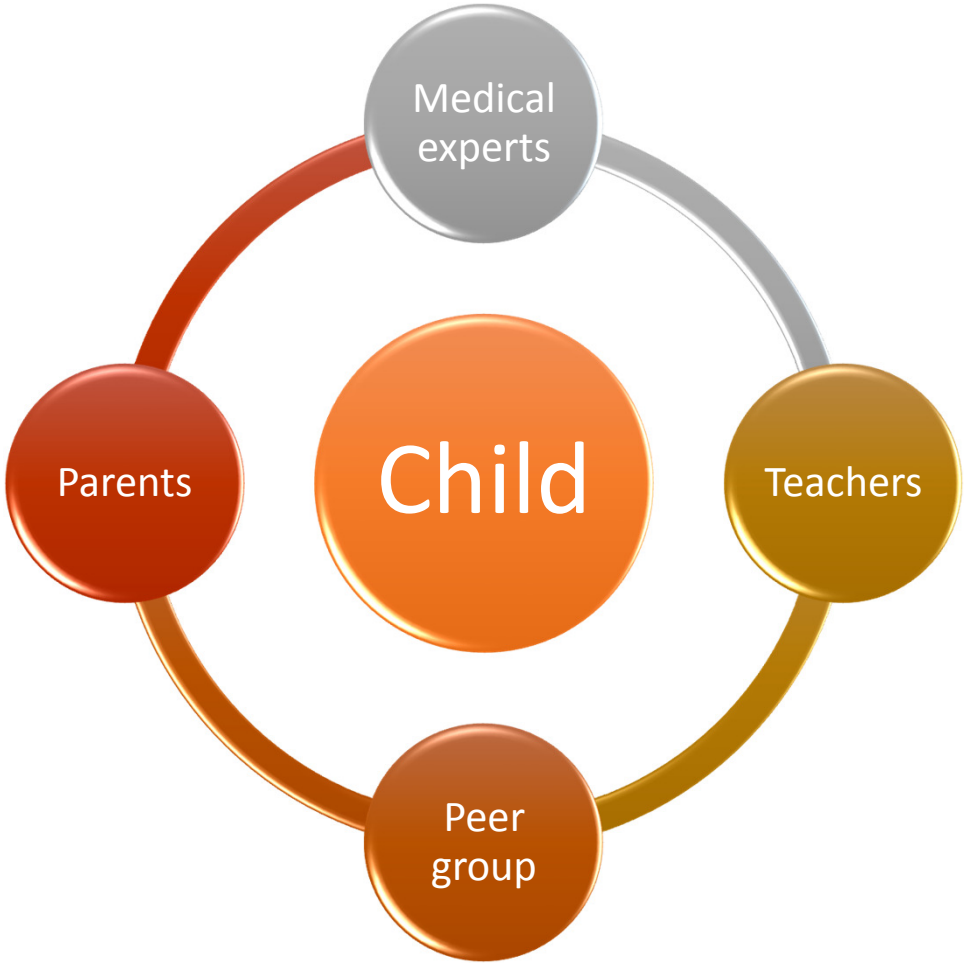
WAGENER STIFTUNG

Promoting development of children with chronic complex conditions – challenges and solutions

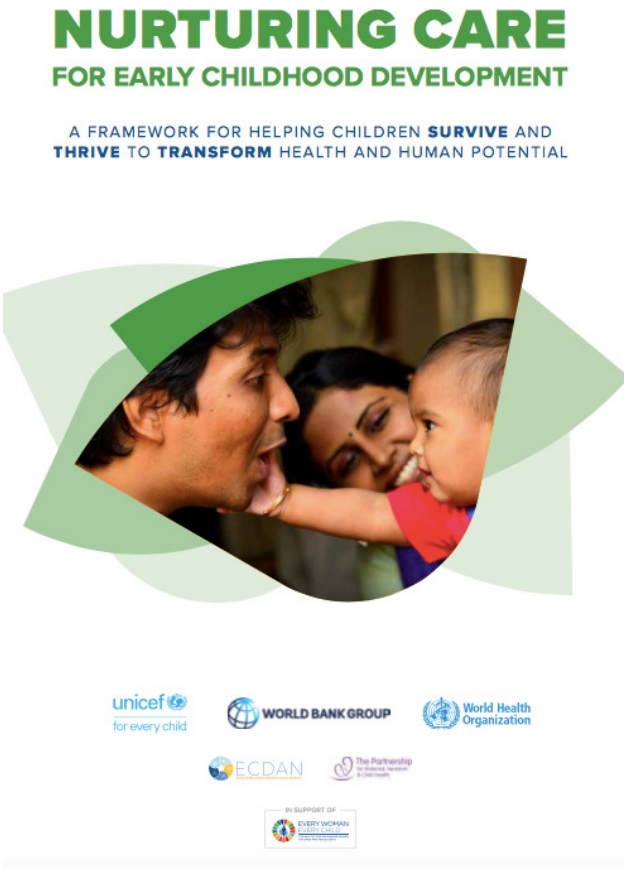
- Challenges in chronic complex conditions
  - ✓ Cerebral palsy
  - ✓ „New Morbidities“
- Social Pediatric Centers in Germany
  - ✓ From basic to specialized care
  - ✓ MBS and EKPSAT

Challenges in chronic complex conditions





Challenges in chronic complex conditions
„New morbidities“ – Luxury problems?



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S. Wiegand · A. Dannemann · Z. Vahabzadeh · M. Ernst · H. Krude · A. Grüters
Interdisziplinäres Sozialpädiatrisches Zentrum und Institut für pädiatrische Endokrinologie und Diabetologie, CCV, Universitätsmedizin Berlin

Wer braucht was?

Neue Ansätze der multidisziplinären Diagnostik und Therapie adipöser Kinder und Jugendlicher in einer multiethnischen Großstadt

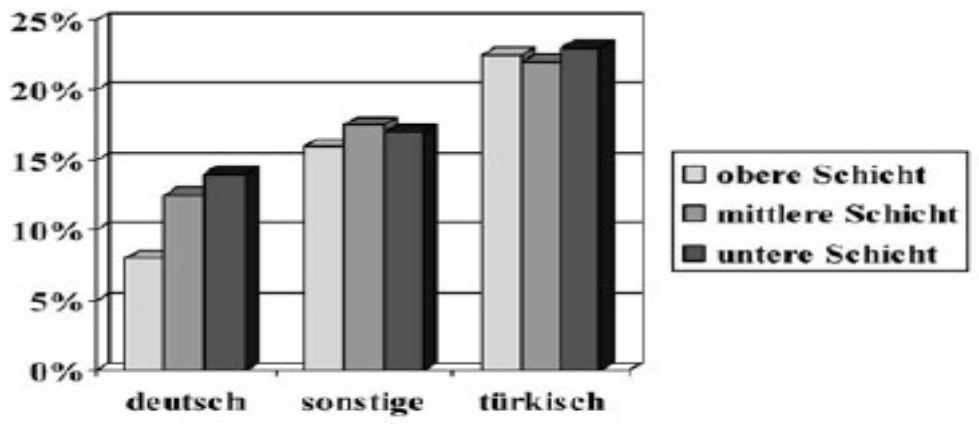
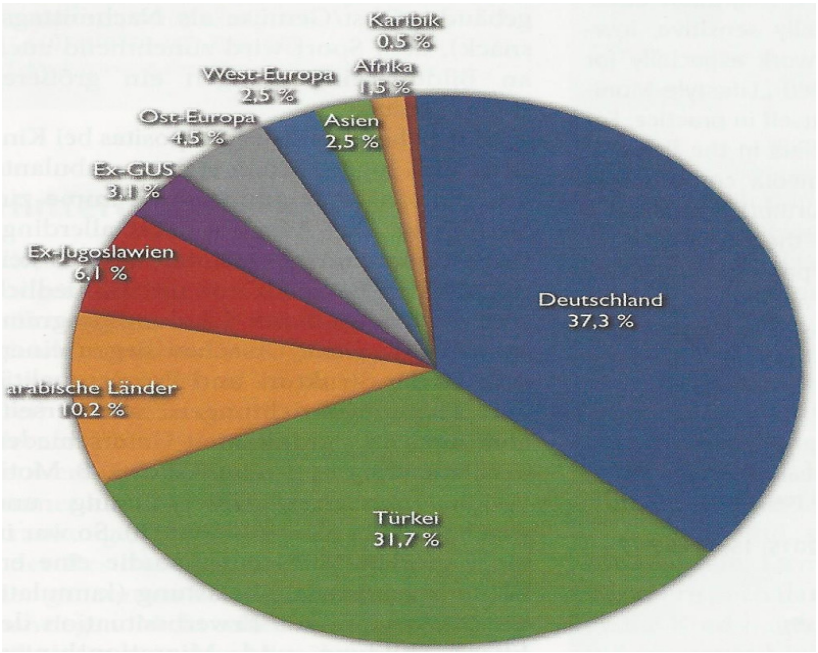


Abb. 3 ▲ **Adipöse Kinder (*RC*) bei der Schuleingangsuntersuchung in Berlin 2001. Differenziert nach Staatsangehörigkeit und sozialer Schicht**



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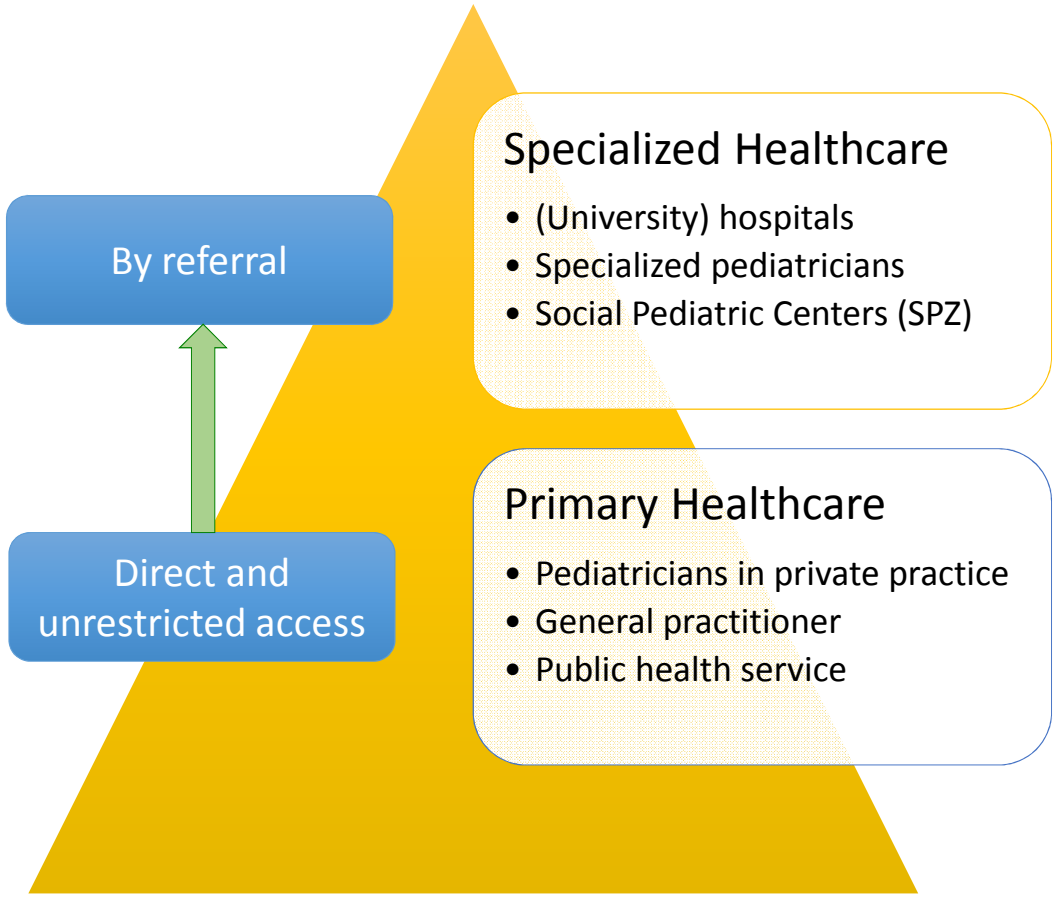
Categories for therapy planning for children and adolescents with obesity (n=266)				
	A (2.6%)	B (33.5%)	C (43.6%)	D (20.3%)
Target planning	Realistic	Unrealistic	Unrealistic	Unrealistic
Suffering	Present, adequate	High	Low	High or low
Motivation	High	Present	Low	Low, resignation
Familial situation	Stable	Unsteady	Unsteady, difficult	Very difficult
Psychosozial problems	None	Present	Often	Psychic problems (child)
Comorbidities	None	Rare	Often	Present
Therapy	Obesity programs (pediatrician, group)	Pediatrician, ambulatory intensive program, educational counseling	Pediatrician (monitoring), therapy of comorbidity	ambulatory intensive program, psychiatrist, long term measure

Ambulatory healthcare for children and adolescents in Germany

- Statutory health insurance
- Private health insurance
- Social welfare



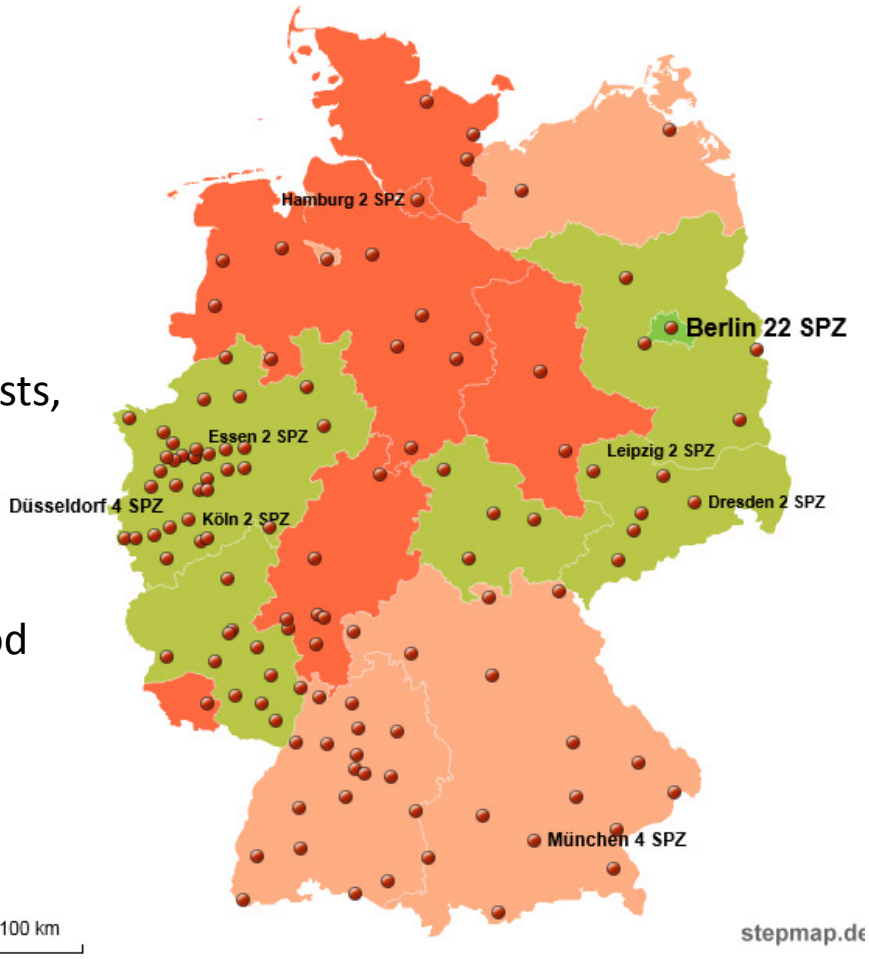
Sozialpädiatrische Zentren (SPZ)
Social Pediatric Centers (SPC)

- Constitution of the first SPC in Munich in 1968 (Theodor Hellbrügge)
- Interdisciplinary approach and multidisciplinary team
- High proportion of psychological and psychosocial interventions
- Family integrated/centered approach
- Small emphasis on somatic aspects
- Continuous long term treatment till adulthood
- Networking (educational service, public health service....)

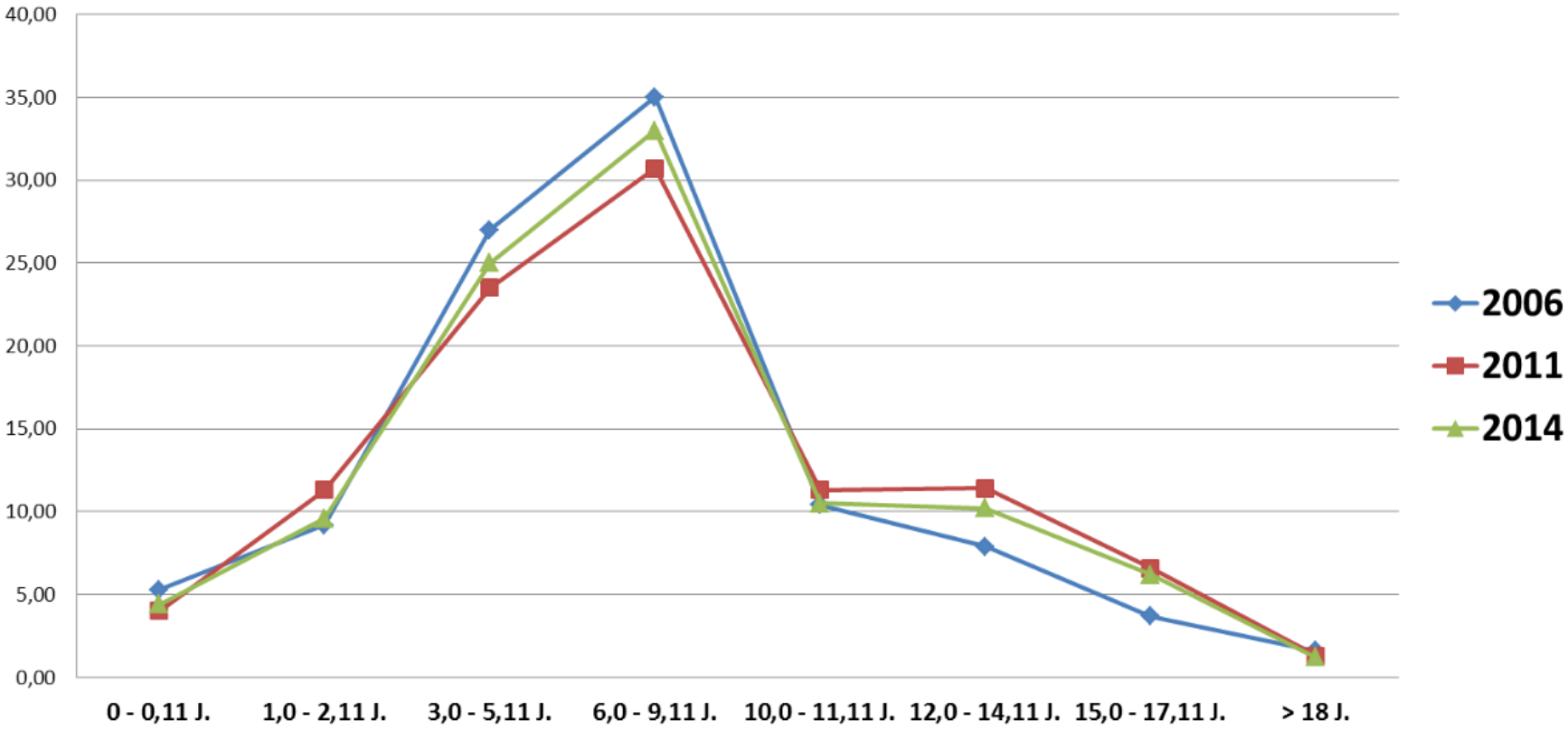
Sozialpädiatrische Zentren
Social Pediatric Centers

- Approximately 150 SPC in Germany
- 350.000 patients in 2014
- 1.100 pediatricians (300 neuropediatricians)
- Psychologists, speech therapists, occupational therapists, physiotherapists, social workers, music therapists, remedial teachers....

- Financed by lump sum per patient and quarterly period



Social Pediatric Centers – Age distribution of patients



Quality standards

- Altöttinger Papier (2003)
- Defining structural quality of a SPC

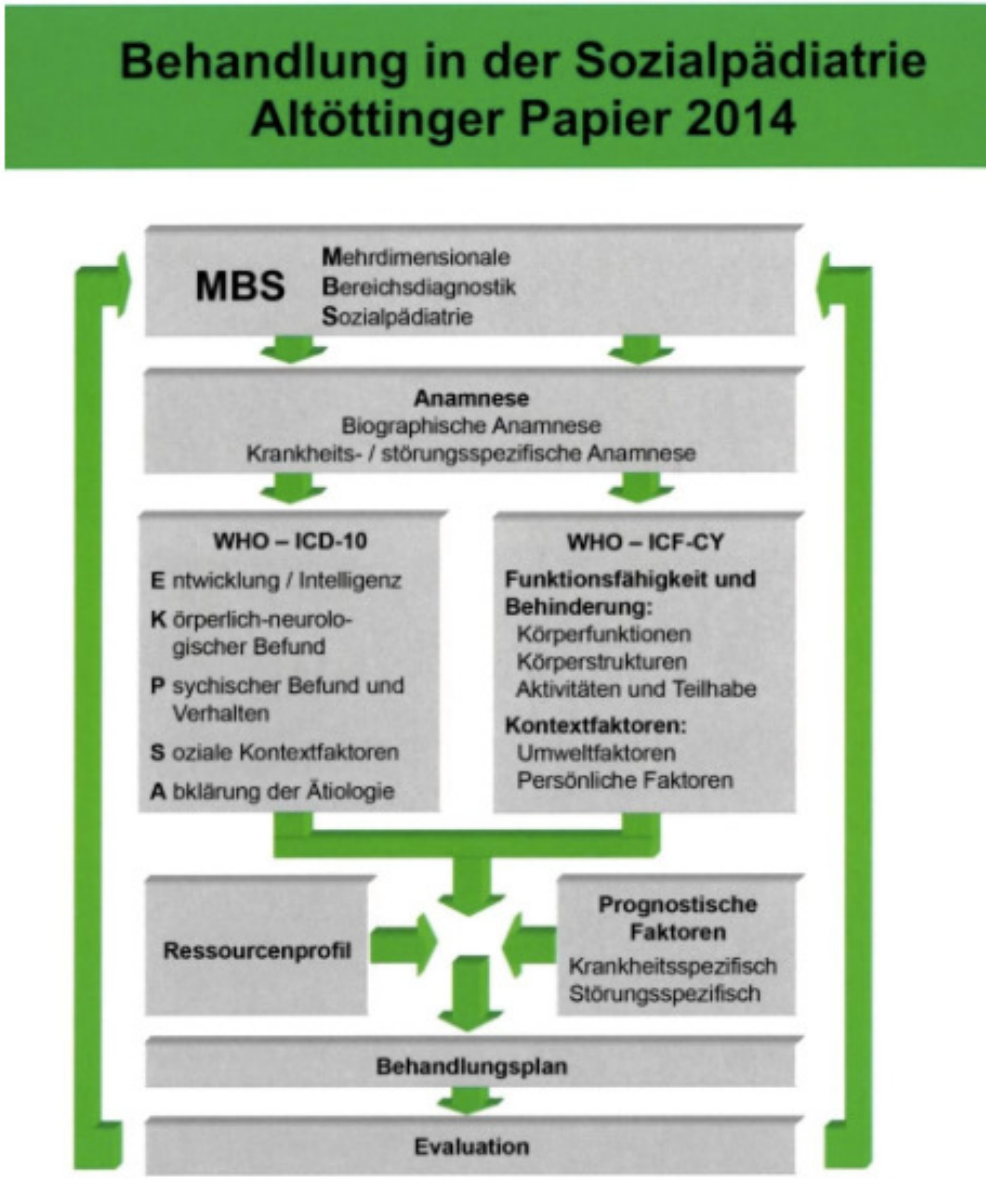
- Further „quality papers“ on different aspects of daily work

Quality standard - MBS

- MBS = Mehrdimensionale Bereichsdiagnostik in der Sozialpädiatrie
- Multidimensional Domain-diagnostics in Social Pediatrics
- Multidimensional Balanced System

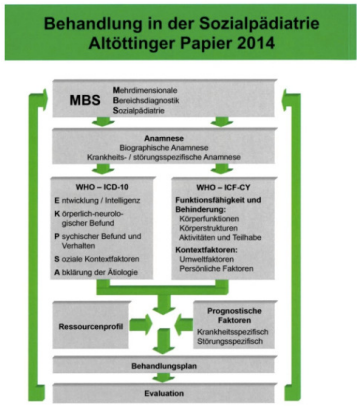
Quality standard – MBS EKPSAT scheme

- Integrating ICF(-CY)
- Resource-orientated



EKPSAT scheme

- E ntwicklung
- K örperlich-neurologische Befunde
- P sychischer Befund
- S ozialer Hintergrund
- A etiologie
- T eilhabe



DESPEP scheme

- Development
- Somatic/neurological findings
- Psychological findings
- Social background
- Etiology
- Participation

EKPSAT scheme – changes of focus over time

	2 years	6 years	13 years
Main problem / diagnosis	**Generalized epilepsy**		
Development	Developmental disorder with main focus on motor and speech development		
Somatic/neurological findings	Generalized epilepsy with GTCS Ataxia		
Psychological findings	Short concentration span		
Social background	Affectionate parental care		
Etiology	Dravet-Syndrom due to SCN1A-mutation		
Participation	Hardly affected		

EKPSAT scheme – changes of focus over time

	2 years	6 years	13 years
Main problem / diagnosis	Generalized epilepsy	**Intellectual disability**	
Development	Developmental disorder with main focus on motor and speech development	Intellectual disability	
Somatic/neurological findings	Generalized epilepsy with GTCS Ataxia	Generalized epilepsy with GTCS	
Psychological findings	Short concentration span	Partial ODD	
Social background	Affectionate parental care	Familial strain	
Etiology	Dravet-Syndrom due to SCN1A-mutation	Dravet-Syndrom due to SCN1A-mutation	
Participation	Hardly affected	Severly restricted participation (learning, communication, self-sufficiency, education)	

EKPSAT scheme – changes of focus over time

	2 years	6 years	13 years
Main problem / diagnosis	Generalized epilepsy	**Intellectual disability**	ODD
Development	Developmental disorder with main focus on motor and speech development	Intellectual disability	Intellectual disability
Somatic/neurological findings	Generalized epilepsy with GTCS Ataxia	Generalized epilepsy with GTCS	Generalized epilepsy with GTCS
Psychological findings	Short concentration span	Partial ODD	ODD
Social background	Affectionate parental care	Familial strain	Single parent
Etiology	Dravet-Syndrom due to SCN1A-mutation	Dravet-Syndrom due to SCN1A-mutation	Dravet-Syndrom due to SCN1A-mutation
Participation	Hardly affected	Severly restricted participation (learning, communication, self-sufficiency, education)	Severly restricted participation (learning, communication, self-sufficiency, education)

Summary

Concerning children and adolescents with complex medical conditions and developmental disorders and their families

- Social pediatric centers are an important factor with respect to an holistic approach
- MBS and EKPSAT scheme might help (especially newcomers in the field of social pediatrics might profit)