

The Journal of Intellectual Disability Research-Abstract Booklet for the 13th European Congress of Mental Health in Intellectual Disability – Berlin 2021

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Congress Programme

Thursday 23/9	Type	ID	Title	Presenting Author	Language	Theater		
2:00-3:30 pm	Keynote	2:00pm	Living with autism - an encouragement	Christine Preißmann	E/G	Humboldt		
	Special Lecture	2:45pm	Hack your brain - unlock your unique potential	Karolien Notebaert	E/G			
	SoS-15 E/OS	106	From vulnerability to resilience: Visualising strengths in people with intellectual disabilities			E/G	Kleist	
		108	Resilience in the face of adversity: How people with intellectual disabilities deal with challenging times		Femke Scheffers			
		111	Crippled collaborations: Disability as a methodological starting point in academic research		Leonie Dronkert			
			141	Perspectives on burdens, strengths and desires of children with neurodevelopmental disorders in residential care		Gabriëlle Mercera		
	IS-3 E/OS	IS-3 E/OS: Treatment				E	Einstein	
			147	Evaluating Talking Mats™ with the inpatient intellectual disability forensic population				Sam Quinn
			114	Design and testing of a virtual reality mentalization module				Paula Sterkenburg
			199	The importance of the emotional development in the musictherapy with individuals with intellectual disability				Federico Fiumani
		168	WIELD 2: Using a picture book to improve epilepsy management for people with learning disabilities		Georgina Parkes			
		88	Smoking cessation in people with mild intellectual disability (MID): a motivational approach		Marieke Meppelder			

CpS-4 G/OL	36	Supporting persons with ID participating in crisis	Priya-Lena Riedel; Barbara Juen; Georg Willeit	G	Kepler
SoS-1 E/OS	178	Treatment at your doorstep: Innovative healthcare with 'The Banjaard Bus'		E	Edison
	192	Treatment at your doorstep : "GIJS: from idea to reality"	CLM van Vliet		
	193	Treatment at your doorstep : Different treatments in a safeand homely atmosphere setting	KC Dekker		
	194	Treatment at your doorstep : "Playing and Recovering on Wheels"	EMN van Ooijen		
SoS-22 E/OL	256	Enhancing the communication between individuals with multiple disabilities and their communication partners		E	Voltaire
	258	Effects of 'Tell it!' on the communication abilities of individuals with congenital Deafblindness	Marianne Rorije		
	260	Joint attention and shared enjoyment in storytelling for individuals with multiple disabilities	Rita Gerkema- Nijhof		
	264	Effects of sensory enhanced interactive story telling (SEIS-T) for individuals with multiple disabilities	Nina Wolters- Leermakers		
IS-1 E/OS		IS-1 E/OS: Health Inequalities/Challenging behaviour		E	Pasteur
	72	Adverse experiences, stress and resilience in the lives of elderly people with intellectual disability	Hadewych Schepens		
	27	Measures preventing challenging behaviour of adults with ID in Swiss residential institutions	Eva Büschi		
	21	Supporting adults with ID and CB in Swiss residential care: Towards an ecological systems approach.	Stefania Calabrese		
	150	Health literacy in people with intellectual disabilities: Strengths and weaknesses	Nils Sebastian Vetter		
	215	Increased susceptibility of Covid-19 diagnosis in Down-Syndrome compared to the general population	Asaad Baksh		

4:00-5:30 pm	Keynote	4:00pm	Alzheimer's disease in Down syndrome - from understanding pathology to prevention	Andre Strydom	E/G	Humboldt
	Historical Lecture	4:45pm	The extinction of people with disabilities during the Nazi regime	Michael Seidel	E/G	
	RT-5 E/OS	214	The assessment and treatment of ASD and/or attachment disorders in persons with an intellectual disability	Paula Sterkenburg; Rita Erlewein; Mark Hudson OL; Mirjam Wouda; Veerle Andries	E/G	Kleist
	SoS-16 E/OS	129	Peer-influence in persons with ID: From science to practice	Verena Hofmann	E	Einstein
		133	Language skills and social contact among students with intellectual disabilities in special needs Schools			
		134	Social and non-social influence on social judgments in adolescents with intellectual disability			
		135	Peer influence on autistic behavior development			
		136	Susceptibility to social influence: a way to promote positive development?			
SoS-24 G/OS	148	Participatory approaches to health promotion with people with intellectual disability	Reinhard Burtscher	G	Kepler	
	151	Participatory development of a health education program for people with intellectual disability				
	209	Health literacy in the field of substance use by and for people with intellectual disabilities (SKoL-Toolbox)				
	210	With enthusiasm and energy: Promoting physical activity in people with intellectual disabilities				
CpS-1 E/OS	109	Addressing sleep disorders in intellectual disability	David O'Regan; Alexander Nesbitt; Ken Courtenay	E	Edison	
SoS-23 E/OL	104	Crisis care for people with intellectual disabilities who display challenging behaviour		E	Voltaire	

		105	Psychosocial interventions for aggression in people with intellectual disabilities	David Prior			
		115	Clinical effectiveness of intensive support teams for challenging behaviour	Ian Hall			
		117	Views and experiences from multiple stakeholders of intensive support teams	Leila Hamza			
		118	Cost effectiveness of intensive support teams for challenging behaviour	Angela Hassiotis			
	SoS-5 E/OS	266	Towards a diagnostic standard in detecting autism spectrum disorders in adults with intellectual disability		Hauke Hermann Isabell Gaul Friedemann Trutzenberg Thomas Bergmann	E	Pasteur
		267	Validation of the German version of the PDD-MRS in an adult sample with ID and suspect of ASD				
		269	Validation of the DIBAS-R in an independent sample of adults with ID				
		270	Replication of the diagnostic validity of the Music-based Scale for Autism Diagnostics (MUSAD)				
		273	The convergent validity of ASD measures in adults with intellectual disabilities				

Friday 24/9	Type	ID	Title	Presenting Author	Language	Theater
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9:00-10:30 am	Meet the Expert	9:00am	Psychotropic drug use in intellectual disability and low-functioning autism spectrum disorder: Who, what, when, how, and why	Marco Bertelli	E/G	Humboldt
	Keynote	9:45am	From neurodiversity to neuroharmony: intellectual disability, autism and happiness	Peter Vermeulen	E/G	
	SoS-2 E/OS	76	ADHD in people with intellectual disabilities- Challenges and dilemmas	Bhathika Perera Ken Courtenay Evan Yacoub	E/G	Kleist
		303	ADHD in ID: Findings from the UK National Audit			
		304	ADHD in ID: Royal College of Psychiatrists Report UK			
		305	Defining functional impairment in People with ADHD and ID			
SoS-6 E/OS	265	Complex case ask for caregiver. Haim Omer and Anton Dösen give the answer		E	Einstein	

		272	An integrative framework: New authority and emotional development	Marleen Schryvers; Goedele Hoefnagels			
		274	Integrating the New Authority and Emotional Development Model in Practice	Cornelia van Ham; Goedele Hoefnagels			
		275	The pros and cons of the integrative framework: New authority and emotional development	Ellen van de Vliet; Willem De Muer			
		IS-17 G/OS: Psychopharmacotherapy					
	IS-17 G/OS	51	Adequacy of drug prescription in adults with intellectual disability in an inpatient unit in Geneva	Markus Kosel	G	Kepler	
		56	More Drugs, less psychotherapy – a retrospective analysis of routine data	Florian Metzger			
		137	Psychopharmacological treatment of adults with intellectual disabilities and Autism-Spectrum Disorder	Matthias Dose			
		110	Of the necessary interplay of therapy and pedagogy in psychiatric hospitals for children with ID	Karolin Kuhn; Katja Albertowski			
		95	Impairment of the serotonergic system in temper outbursts in PWS and treatment with SSRIs	Maximilian Deest OL			
		165	Mental health care for adults with mild intellectual disabilities: Four studies using Dutch health data		E	Edison	
	SoS-13 E/OS	171	Mental healthcare for adults with mild intellectual disabilities: a cohort study in Dutch primary care	Katrien Pouls			
		173	Mental healthcare for adults with mild intellectual disabilities: a detailed description of GP care	Bianca Schalk			
		174	Mental healthcare for adults with mild intellectual disabilities: Urgent care within out-of-hours GP services	Monique Koks-Leensen			
		182	Mental healthcare for adults with mild intellectual disabilities: a cohort study in Dutch mental healthcare	Katrien Pouls			
		IS-15 E/OL: COVID-19				E	Voltaire
	IS-15 E/OL	289	Perspectives on the experiences of people with intellectual difficulties during the Covid-19 pandemic	Silviya P Nikolova			

		237	Understanding inequalities in COVID-19 outcomes following hospital admission for people with ID	Sarah Pape		
		37	COVID-19 impact in people with intellectual disabilities	Mercedes H Núñez-Polo		
	SoS-8 E/OS	252	Dementia in persons with ID – a rare condition or of everyday relevance?		E	Pasteur
		259	Assessment of dementia in a clinical sample of persons with intellectual disability	Peggy Rösner		
		261	Detection of dementia in individuals with intellectual disability using the DTIM - preliminary results	Peggy Rösner		
		262	German translation and validation of the CAMDEX-DS	Sandra V. Loosli		
263	The use of biomarkers for the diagnosis of Alzheimer's disease (AD) in Down syndrome (DS)	Sabine Lindquist				

11:00-12:30 am	State of the Art	11:00am	Building resilience: Researching the practice of mindfulness and acceptance and commitment therapy with family carers of adults with learning disability and challenging behaviour	Tina Cook	E/G	Humboldt
	State of the Art	11:45am	Mental health of deaf people with intellectual disabilities	Johannes Fellingner	E/G	
	SoS-3 E/OS	292	Improving mental health for individuals with developmental disabilities: Results from clinical research		E/G	Kleist
		293	Behavioural equivalents of schizophrenia in patients with intellectual disability and autism	Trine Lise Bakken		
		294	Experiences of ward atmosphere in inpatients with intellectual disability and mental illness	Heidi Sageng Sommerstad; Trine Lise Bakken		
		295	Patients with intellectual disabilities in specialist mental health services in Singapore	Jonathan Ee		
		296	Evaluation of a multimodal group training supporting People with Autism and intellectual Disability	Thomas Bergmann		
	IS-2 E/OS	33	IS-2 E/OS: Autism and developmental delays Psychometric properties of the Psychopathology in Autism Checklist (PAC) in adolescences and adults	Sissel Berge Helverschou	E	Einstein
		227	Diagnosis of Autism-Spectrum disorder in adults with intellectual disabilities	Matthias Dose		

		121	Deficit or Delay? Executive functions in 8 to 17-year-olds with borderline intellectual functioning	Maaïke van Rest		
		30	The social-emotional functioning of young children with a significant cognitive and motor developmental delay	Ines Van keer		
	RT-6 G/OS	277	Covid-19 pandemic and its consequences for people with intellectual and developmental disabilities	Michael Seidel; Annika Kleischmann; Marcus Bernard; Brian Fergus Barrett; Wolfgang Koeller	G	Kepler
	CpS-2 E/OS	164	Co-presentation with people with intellectual disabilities, employment, education, inclusion	Ruwani Ampegama; Karina Marshall-Tate; Maggie Brennan; Eddie Chaplin; Steve Hardy; Peter Cronin	E	Edison
			IS-13 E/OL: Health promotion			
		241	Daily time management and time-assistive devices for people with an intellectual disability	<i>Debora van Elst</i>		
		146	Design to implementation of technology-based interventions for visual (and intellectual) disability	<i>Vernandi Dyzel</i>		
	IS-13 E/OL	170	E-health, physical activity and intellectual disability –protocol for a pilot study	<i>Henriette Michalsen</i>	E	Voltaire
		123	How do multimorbidity and lifestyle factors impact the perceived health of adults with intellectual disabilities?	<i>Monica Isabel Olsen</i>		
		185	Physical and mental health in intellectual disability, preliminary data of a cross-sectional study	<i>Martina Capellazzi</i>		
			Validity analysis and clinical impact of the Scale of Emotional Development-Short			
	SoS-9 E/OS	251	Validity analysis and clinical impact of the Scale of Emotional Development-Short			
		253	Item-validity analysis of the SED-S in a multicenter sample of adults with intellectual disabilities	Hauke Hermann	E	Pasteur
		254	Behavioural phenomena in persons with an ID according to Emotional Development	Nadine Berndt		
		255	Seed the SED-S: does emotional development predict psychiatric disorders in people with intellectual disability?	Aleksey Lytochkin		

		257	The impact of depressive episodes on the level of emotional development in adults with IDD	Maria Schmidt		
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2:00-3:30 pm	Keynote Meet the Expert	2:00pm	Focus on the brain: How individual genes, prenatal epigenetic characteristics and early interaction experiences shape resilience and risk	Nicole Strüber	E/G	Humboldt
		2:45pm	Blind spots! A look at some of the outcomes of Norwegian reform in service systems for persons with intellectual developmental disabilities	Karl Elling Ellingsen	E/G	
	SoS-7 E/OS	268	People with intellectual disabilities in prison and court settings in the UK	Jane McCarthy Jane McCarthy; Denise Harvey Eddie Chaplin Salma Ali; Karina Tate-Marshall	E/G	Kleist
		125	Vulnerabilities of Prisoners with Autistic Traits			
		126	People with intellectual disability within Court Liaison & Diversion Services: characteristics & vulnerabilities			
		131	Identifying and managing intellectual disability in prisons			
		271	People with intellectual disabilities views on support following court contact			
	IS-4 E/OS	IS-4 E/OS: Inclusion, society and community		Friederike Koch; Karin Tiesmeyer Vicky Simitopoulou Evy Meys Luise Schröder Sophia Arndt	E	Einstein
		124	"This is how I want to live!" Results of a study to identify housing wishes with people with complex disabilities			
		287	CONF.I.A.N.Ç.A a moment of stillness, self-reflection and connection			
22		Identifying and linking leverage points to inventions based on 'dynamic personal network stories'				
113		Psychology students' education, experiences & attitudes toward people with intellectual disabilities				
189	Inclusion and participation of people with intellectual disability and challenging behaviour					
SoS-26 G/OS	47	Recommendations of the DGMGB for the medical care of patients with ID		G	Kepler	

		196	Functional deterioration in adults with cerebral palsies – the differential diagnosis	Peter Martin		
		197	Pain in adults with developmental disorders – From symptom to diagnosis	Jörg Stockmann		
		198	The differential diagnosis of diarrhea in adult patients with intellectual disabilities (ID)	Martin Rohlf		
	RT-1 E/OS	31	An international manual emotional development and intellectual disability	Jac de Bruijn; Jolanda Vonk; Filip Morisse; Els Ronsse	E	Edison
	IS-12 E/OL		IS-12 E/OL: Assessment			
		144	Assessing conversational skills of adolescents and young adults with developmental disabilities (DD)	<i>Silvia Iacomini</i>		
		163	Autism screening in adults with intellectual disability and hearing loss: validity of the DIBAS-R and PDD-MRS	<i>Johannes Hofer</i>	E	Voltaire
		91	Influence of emotional development, mental disorders and problem behaviors in a population simple with ID	<i>Carlos Peña-Salazar</i>		
		43	What we need to know about callous-unemotional traits and youths functioning?	<i>Myriam Squillaci</i>		
	SoS-14 E/OS	157	Focus on personalised care and individual behavioural change for improving mental health in IDD			
		158	Lessons about the feasibility of daily diary monitoring in youth with MID-BIF	Daan Hulsmans		
		161	The effectiveness of a personalized treatment for substance use disorder in people with MID-BIF	Lotte Gosens	E	Pasteur
		179	Treatment of self-harming and suicidal behaviour in IDD by adapted dialectical behaviour therapy	Annemarie van Vonderen		
		180	Physiological stress as early-warning signal for challenging behaviour in people with SPID	Rianne Simons		

4:00 - 5:20 pm	Keynote	4:00pm	Enhancing the wellbeing of people with severe intellectual disability and complex needs	Chris Oliver	E/G	Humboldt
	Meet the Expert	4:40pm	Parents with intellectual disabilities: (evidenced based) intervention programs, best practices and parents' stories	Marja Hodes	E/G	

SoS-17 E/OS	96	From theoretical models, through psychotropic drug prescriptions practice, to patient's reported outcome measures		E/G	Kleist
	97	Use of integrative models in the assessment of challenging behaviour in individuals with intellectual disabilities	Tryntsje Fokkema		
	98	Challenging behaviour, psychotropic drug prescription and restrictive measures: how do they relate?	Josien Jonker		
	99	Discontinuation of antipsychotic drugs for challenging behaviour; a survey on prescribers' experiences and opinions	Joke de Haan		
	100	Inclusive research on outcome measures for pharmaceutical treatments of challenging behaviour	Gerda de Kuijper		
IS-7 E/OS	IS-7 E/OS: Mental Disorders			E	Einstein
	40	Identification of post-traumatic stress disorder in autistic adults with intellectual disabilities	Arvid Nikolai Kildahl		
	73	Dementia in intellectual disability: a training course for daily caregivers	Hadewych Schepens		
	224	Identifying the links between common mental health conditions and dementia onset in a Down syndrome cohort	Mina Idris		
	34	Inventory for supported psychological evaluation (iSpe) – a research-based innovation project	Oddbjørn Hove		
188	Measuring stress levels: suitability of self-report stress measures for people with MID/BIF	Roel Kooijmans			
4:00-4:40 pm: RT-8 G/OS	86	The effects of attachment disorders during childhood of people with intellectual disabilities	Detlef Meyer OL; Dorothee Hillenbrand; Martin Rothaug	G	Kepler
4:40-5:20 pm: RT-7 G/OS	122	"This is how I want to live!" Results of a study to identify housing wishes with people with complex disabilities	Karin Tiesmeyer; Friederike Koch; Sandra Waters; Si-yeun Hammerbacher		

SoS-4 E/OS	276	From practice to research. Arts-based interventions in adults with intellectual disabilities			
	279	AutCom: Musical-bodily interventions in supporting adults with intellectual disability and autism	Thomas Bergmann	E	Edison
	280	The art therapy interventions for an individual with Down Syndrome	Magdalena Rubeša		
	281	Improvisational drama therapy for people with intellectual disabilities and mental health problems	Regina Fabian, Daria Tarasova		
	282	Music therapy interventions for affect regulation in adults with severe multiple disabilities	Silke Reimer		
IS-11 E/OL: Inclusion, society and community					
IS-11 E/OL	222	A study of parental perspectives on tutoring sessions for children with disabilities during COVID-19	Zamira Hyseni Duraku; Mirjeta Nagavci	E	Voltaire
	35	Building a community forensic service for people with intellectual disabilities and autism	Leah Wooster		
	221	Gender Incongruence and intellectual disability - What services are provided for this population?	Vinicius Faccin Bampi		
	228	Some aspects of community participation of adults with psychosocial disabilities	Rea Fulgosi-Masnja		
	139	Befriending in adults with intellectual disability and depressive symptoms: A pilot trial	Afia Ali		
SoS-11 E/OS	230	How to treat/support adults with ID and MH problems and their environment? An example of matched care		E	Pasteur
	233	Treatment model for adults with ID and MH problems: a continuum of inpatient and outpatient care	Filip Morisse		
	234	Case study of an 18-year-old female (mild ID and ASD) admitted in the admission unit for youngsters	Suzan Laureys		
	235	Case study: man with moderate ID, epilepsy and psychosis admitted in a short term psychiatric unit	Saskia Rigolle		
	236	Outreach trajectory with the context of a woman with mild ID and neurodevelopmental disorder	Leen De Neve		

5:30 - 7:00 pm	Meet the Expert	5:30pm	Lessons from a global pandemic: What have we learned?	Jeanne Farr	E/G	Humboldt
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	Special Lecture	6:15pm	SPECTROM - an online training programme to reduce overmedication of people with ID	Shoumitro (Shoumi) Deb; Bharati Limbu	E/G	
	SoS-20 E/OS	48 50 52 53 54	Validation and extensions of the scale of emotional Development – Short Validation and extensions of the scale of emotional Development – Short Validation and extensions of the scale of emotional Development – Short Validation and extensions of the scale of emotional Development – Short Validation and extensions of the scale of emotional Development – Short	Miriam Flachsmeyer Theresa Meinecke Daria Tarasova Sabrina Lutter	E/G	Kleist
	IS-8 E/OS	32 153 219 23 217	IS-8 E/OS: Models of care and support Beyond ‘spheres of exclusion’. Individualized support for persons with complex needs Forms of support for patients with comorbid intellectual disabilities and psychiatric disorders in Poland Model of interdisciplinary outpatient care Predictors of mental health crises among People with intellectual/developmental disabilities in the START Program Systemical impact of socio-emotional diagnostics	Martin F. Reichstein Krzysztof Krysta Rita Maria Erlewein Luther Kalb Rita Maria Erlewein	E	Einstein
	IS-16 G/OS	226 290 166 232 186	IS-16 G/OS: Quality of life and wellbeing Adaptive profiles of deaf adults with ID: ID domain discrepancies and quality of life Assessment of psychological distress in people with intellectual disabilities Health care for people with impairments considering the social participation model Mood in the corona pandemic in a therapeutic community for the deaf with intellectual disabilities The topic of health in the life stories of people with intellectual disabilities	Johanna Eisinger; Magdalena Dall Melanie Jagla-Franke Christian Henning Clemens Schaurhofer Hanna Stahlhut OL	G	Kepler

	SoS-19 E/OS	58	Peer relations and problem behaviors in children and adolescents with intellectual disabilities				
		59	Effects of problem behavior on acceptance and rejection of students with ID in special needs schools	Noemi Schoop-Kasteler	E	Edison	
		60	Is problem behavior development of students with ID influenced by their classmates' characteristics?	Christoph Müller			
		61	Training resistance to peer influence in adolescents with mild-to-borderline intellectual disability	Eline Wagemaker			
	IS-14 E/OL			IS-14 E/OL: Child and adolescent			
		283	Effect of the use of an iPad on the attention span of a child with Smith Magenis Syndrome: a single case study	<i>M.T. Rikken-Evers</i>			
		162	Autonomy restrictions & custodial measures from the perspective of adolescents with intellectual disabilities	<i>Saskia Schuppener</i>	E	Voltaire	
		284	Needs of teachers regarding the education of children with learning difficulties	<i>Claudia Iacob</i>			
	SoS-25 G/OS	44	Verbal behavior for school-aged children with Autism Spectrum Disorder: what does the literature say?	<i>Myriam Squillaci</i>			
		25	Treatment and educational support for people with intellectual disabilities and trauma-related disorders				
		63	Narrative exposure therapy in people with intellectual or psychol. disability-results of a study	Birgit Mayer	G	Pasteur	
		67	Narrative and imaginary methods in the treatment of childhood abuse traum – a case study	Marie Ilic			
		71	Severe developmental trauma and the educational and therapeutic work using the BEP-KI-k	Birgit Mayer			

Saturday 25/9	Type	ID	Title	Presenting Author	Language	Theater
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9:00 -10:30 am	Meet the Expert	9:00am	Emotional development in persons with intellectual disabilities	Filip Morisse; Leen de Neve	E/G	Humboldt
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State of the Art	9:45am	Biology of dissociation: current findings from stress research	Kim Hinkelmann	E/G	
9:00-9:40 am RT-2 E/OS	138	Mental health & intellectual disabilities; a transdiagnostic approach to improve practice & research	Gerda de Kuijper; Josien Jonker; Joke de Haan; Tryntsje Fokkema	E/G	Kleist
9:45 - 10:30 am CpS-3 E/OL	297	Beyond Words - tools for empowering people	<i>Sheila Hollins; Irene Tuffrey-Wijne; Noelle Blackman; Karolyn Kuhn</i>		
IS-10 E/OS	218	Compassion focused therapy for people with intellectual disability: a scoping literature review	Hannelies Hokke	E	Einstein
	223	Integrative multidisciplinary approach to mental health of persons with IDD	Ljilja Ivanković		
	195	Pain recognition in children and adults with rare genetic syndromes and intellectual disability	Helen Korving		
	116	Predictors of job satisfaction among staff in care settings for individuals with intellectual disability	Jana Leukart Guido Semrau		
	155	Quality of Life of Parents Caring for Adult Children with Intellectual Disability	Tamara Kralj		
IS-19 G/OS	69	IS-19 G/OS: Treatment and care Advance Care Planning (ACP) for people with impairments	Theodore Otto-Achenbach	G	Kepler
	247	Cognitive und emotional development in a sample of individuals who are deaf and have intellectual disabilities (ID)	Joachim Adl		
	149	Network for competence development in working with people with CB and intensive assistance needs	Si-yeun Hammerbacher		
	74	Social skill training for handicapped people: A new approach	Antonia von Weizsäcker		
	70	Treatment planning based on Advance Care Planning (ACP) for practical application	Sandra Menci		
SoS-12 E/OS	200	Fetal Alcohol Spectrum Disorder (FASD) in ID		E	Edison
	203	Fetal alcohol spectrum disorder (FASD) – only relevant for children?	Björn Kruse		
	206	Fetal Alcohol Spectrum Disorder (FASD) in Children and Adolescents. Focussing on Invisible Impairments	Jörg Liesegang		

		207	Neuropsychological outcome in adults with FASD and intellectual and developmental disorder	Jessica Wagner		
		208	Substance use, comorbid psychiatric disorders and suicide attempts in adult FASD patients	Rosa Stoll		
			IS-5 E/OS: Ethics and spirituality			
	IS-5 E/OS	216	Better Health - Better Lives, a 10 year review of the WHO europe declaration	Nathaniel Scherer	E	Voltaire
		286	Disgust – a long-acting mechanism for social exclusion of people with intellectual disabilities	Michael Seidel		
		103	Issues of research ethics in the context of so-called mental and/or multiple disabilities	Markus Dederich		
		288	Leo Kanner - a strong opponent of euthanasia in “feebleminded” children	Michael Seidel		
		239	Spirituality and quality of life in individuals who are deaf and have ID	Maria Fellingner; Johannes Fellingner		
	9:00-9:40 am RT-4 E/OS	298	Practical implications from embedding a trauma-informed approach in response to ‘Transforming Care’	Robert Ferris- Rogers; Wendy Ewins; Noelle Blackman	E	Pasteur
	9:45-10:30 am RT-3 E/OS	87	Practical implications for discharge of restricted patients in England	Robert Ferris- Rogers; Dr Roger Banks; Christine Hutchinson		

11:00-12:30 pm	Keynote	11:00am	New insights on psychopathological assessment in persons with intellectual disability and low-functioning autism spectrum disorder	Marco Bertelli	E/G	Humboldt
	SoS-18 E/OS	80	The CCE Approach: Intervening in the situations of residents with severe challenging behaviour		E/G	Kleist
		82	Using dialogue to assess the quality of life of a person with severe multiple Disabilities	Anouschka Jansen		
		83	A good practice in cases of Self-Injurious behaviour in people with intellectual disabilities	Peter Koedoot		
		84	The organisational environment of residents with intellectual disabilities and challenging behaviour	Vanessa Olivier- Pijpers		

IS-9 E/OS	IS-9 E/OS: Multiple and profound disabilities			
	160	Assessment of social communication skills in adults with intellectual disability and deafness	Daniel Holzinger	
	24	Attachment psychoeducation for parents of children with severe disabilities: A micro-intervention	Sien Vandesande	
	240	Designing a system that supports caregivers of people with severe/profound intellectual disabilities	Kyra Frederiks	E Einstein
	120	Self-Determination of individuals with extensive and complex support needs	Jacqueline van Tuyll van Serooskerken	
26	The 'DHG standards' for supporting participation in case of persons with profound intellectual and multiple disabilities	Erik Weber		
IS-18 G/OS	IS-18 G/OS: Child and adolescent			
	102	„Drop the term, challenging behavior!“ – The trivialization of emotional suffering	Klaus Henricke	
	90	Diagnosis and differential diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in adults	Marie Ilic	
	38	Fetal Alcohol Spectrum Disorder (FASD) - Enabling participation for children and adolescents	Jörg Liesegang	G Kepler
	302	School closures affecting pupils with ID during the pandemic: Situation and opportunities from the teachers' and parents' perspective	Steffen Siegemund-Johannsen, Christoph Ratz, Christiane Reuter	
78	Social pediatrics and child and adolescent psychiatry - Existing care options and open professional needs	Loretta Ihme		
SoS-10 E/OS	Who challenges whom? Effects of systemic interventions in the field of ID and challenging behaviour			
	242	Adopting systemic methods in psychiatric contexts: results from the german research project SYMPA-ID	Meike Wehmeyer	E Edison
	244	Maintaining appreciation in a strained psychiatric consultation: benefits of the systemic approach	Kordula Kraus	
	245	From challenge to change: effects of a systemic intervention in a group home setting	Petra Akoh	

SoS-21 E/OL	285	COVID-19 pandemic – effects and challenges in people with intellectual disabilities			
	248	How to address and better prepare for pandemic related trauma experienced by people with intellectual disabilities	<i>Jeanne M Farr</i>	E	Voltaire
	299	COVID-19 and people with intellectual disabilities in the UK – what happened?	<i>Ken Courtenay</i>		
	300	Impact of COVID-19 on families with young children with developmental disabilities	<i>Angela Hassiotis</i>		
	301	Impact of the COVID-19 pandemic on people with disabilities in Germany - results of an online-based survey	Michael Seidel		
IS-6 E/OS		IS-6 E/OS: Families/parenting			
	225	Effects of the pandemic on the mental health of carers of people with ID: Quantitative and qualitative findings	Biza Stenfert-Kroese		
	145	Empowering mothers of children with developmental delays	Tamara Kralj		
	291	Parents mental health and effects of COVID-19 on children with disabilities and their families	Lea Masnjak Šušković	E	Pasteur
	57	Parents of children with disability: coping and resilience	Angelka Keskinova		
	191	Triggers for dysfunctional mental health of mothers raising a child with disabilities – Towards an intervention model	Lianne Dixon		

Editorial – Welcome to the 13th European Congress of Mental Health in Intellectual Disability

This year the 13th EAMHID-Congress will take place from 23rd to 25th of September 2021 in Berlin, Germany. Given the recent pandemic the conference will welcome delegates for the first time both in person and virtually. This special abstract edition acts as a guide to the conference content and includes Keynote, symposia, oral presentations, roundtables, workshops and posters. The Journal of Intellectual Disability Research (JIDR) and EAMHID has a long relationship and published the proceedings of the first conference in Veldhoven (volume 37, supplement 1, 1993).

For those able to attend in person I would like to welcome you to Berlin, a city steeped in History, on behalf of the association's current President Tanja Sappok and Vice President Brian Fergus Barrett. The theme of this year's congress is From Science to practice – improving mental health in persons with intellectual disability. With its various scientific and practice-based formats, the EAMHID 2021 Congress will contribute to improving mental health in people with an intellectual disability by fostering evidence-based treatment and highlighting innovation in support for this highly vulnerable group.

Although great strides forward in the mental health of people with an intellectual disability have been made over the last thirty years, we would like to share some of the history and work of the association to introduce this supplement.

The European Association for Mental Health in Persons with Intellectual Disability (EAMHID) has its roots in the late 1980's. It was formed out of concern society and working professionals for the quality of life of people with an intellectual disability and to address whether the mental health systems currently in place could provide mental health care for people with intellectual disabilities or was there a need for specialised mental health services this unique population. This occurred in the context of different care systems across Europe and the world. For example, in the United Kingdom intellectual disability was already recognised as a psychiatric specialty within the Royal College of Psychiatrists. With pioneers including Ken Day and Nick Bouras leading the changes by developing specialist hospital and community based mental health services for people with an intellectual disability. Whereas in most European countries at this time mental health care for people with an intellectual disability was not a consideration. There were some notable exceptions; for example, in the Netherlands, Anton Dosen created an international professional

network to share knowledge between professionals from different countries and in 1992 organised the “European Experts Conference on Mental Health Care for People with Mental Retardation” in Veldhoven, the conclusion of which led to the formation of a European Association for Mental Health in Mental Retardation (MHMR) or EAMHID as it is now known. The first Executive Committee comprised A. Dosen (NL) President, K. Day (UK) Vice-President, W. Verhoeven (NL) secretary, and the members: C. Gaedt (G), M. van Wallenghem (B) and N. Bouras (UK), with the first Association’s congress taking place in Amsterdam in 1995. Although Europe focussed from the beginning strong relationships and participation from North America, where pioneers such as Frank Menolascino, Ludwig Sczymanski, Robert Sovner, Steven Reiss, William Gardner were examining the specificities of behaviour and psychopathology and related diagnostic difficulties of mental disorders an intellectual disability. These early initiatives and formation of EAMHID led to the development of professional knowledge and skills, and introduced bespoke training and education of professionals and carers involved in the care and support of people with an intellectual disability. These developments were at the forefront of changes to policy on the care for people with an intellectual disability in different European countries.

The EAMHID Congress is held biannually and following the conference in Veldhoven, (which led to the formation of the Association), they have been held in London 1999, Berlin 2001, Rome 2003, Barcelona 2005, Zagreb 2007, Lisbon 2013; Manchester 2015, Luxemburg 2017 and Barcelona 2019. The congress has served to showcase scientific advances in the field as well as developments in practice, services and policy, whilst allowing the exchange of experiences and knowledge between congress participants.

The Association aimed to stimulate and facilitate international cooperation, exchange of knowledge and experiences in the field of mental health care for people with an intellectual disability, with an emphasis on the scientific study, improvement of standards of service provision throughout European countries. Today as it did in the early days, EAMHID provides a platform for academics, health professionals and policy makers. The purpose of the Association is to facilitate international cooperation and exchange of knowledge and experience in the field of mental health in people with an intellectual disability. Special emphasis is placed on the coordination and promotion of scientific activities and improving standards of care and support throughout Europe.

Despite the Association's achievements there is lot more that needs to be done, we strongly believe that the robust network with its strong bonds throughout

Europe will further promote well-being and health of people all over Europe. To help in this mission we invite everybody to engage! With this in mind I would like to thank all EAMHD members and supporters for making this Congress possible, with a special thank you to Lucy Chaplin for her help in editing this abstract edition. Finally I'd like to extend a special thank you to Tanja Sappok, Brian Fergus Barrett, the Board of the Association and the Local Organising Committee in Germany for making this Congress a reality during such a difficult time.

Professor Eddie Chaplin Secretary of the European Association for Mental Health in Persons with Intellectual Disability (EAMHID)

Historical Lecture

The extinction of people with mental and physical disabilities by German physicians during the Nazi time

Michael Seidel

During the Nazi time about 270,000 German citizens with disabilities and mental disorders were compulsorily sterilized due to a Nazi law from July 1933. The haste of its implementation proves the interest of the Nazi state authorities for a biological "solution" to social problems, for purifying the "race" and for saving money for care of future offspring of sick and disabled people.

Another crime was the extermination of people with disabilities. Between 1939 and 1945, about 275,000 - 300,000 people with disabilities were killed. In October 1939 Hitler signed a euthanasia note authorizing his physician Brandt and others to start the secret killing programme (after WW II named Action T4). Selected physicians were authorized to select patients for the "mercy death". The first victims were German citizens. Later citizens of occupied countries (Poland, Bohemia, Belarus, Latvia etc.) were murdered too.

During 1940, mounting rumors of what was taking place spread. Families withdrew their relatives from institutions to care for them at home. Some doctors manipulated the diagnoses of the patients in order to avoid that they fulfill T4 criteria. Some clergymen offered opposition against the killing activities. Pastor F. von Bodelschwingh (director of the Bethel Institution at Bielefeld) and Pastor Braune (director of the Hoffnungstal Institution near Berlin) were among the protesters. Due to the rumors and protests Hitler dictated the end of the T4 killings in August 1941. The planned death total for the programme of 70,000 deaths had been reached. The formal end of the T4 programme did not stop the killing. From the end of 1941 the killing continued, albeit less systematically, until the end of the war.

1945 the allied troops liberated Germany and Europe from the Nazi regime. The

German physicians and their professional organizations started soon to fool the public. They stated that only a small number of fanatic followers of the Nazi ideology were involved. It is, however, well documented that many physicians and nurses were involved. A noticeable number of high-level physicians took part actively in planning and execution of the killings. Only a few physicians opposed actively against the killings, many collaborated.

Researchers suggested various explanations for the crimes: ideological, racial, economic reasons etc. The relation to the beginning of WW II is obvious.

Therefore, the economic reasons played a dominant role. In the meantime, much research has been conducted. Professional organizations and institutions commissioned investigations of their history during the Nazi time.

The historical lecture describes development of the medical crimes, reflect their background and consider the consequences for today and in the future. The most important insight is: The absolute respect for human dignity and unlimited human rights for all people may prevent that such crimes against people with disabilities may recur.

Simple and to the point:

- During the Nazi era, 270,000 people with disabilities and mental disorders were forcibly sterilized and up to 300,000 people with disabilities were murdered
- However, the secret killing program became known in 1940 and there was resistance among the German population
- In 1941, the systematic killing was stopped, but the murder continued until the end of the war, for example by depriving people of food.
- Many high-ranking doctors and medical personnel actively participated in the planning and execution of the killings
- After the war, medical professional associations claimed that only a small number of fanatical followers of Nazi ideology were involved in the killings
- Conclusion of the late reappraisal is that only full respect for the dignity and rights of all humans can prevent such crimes against people with disabilities

Keynotes

Profile Karolien Notebaert, Ph.D.



With a Ph.D. in Neurosciences, Karolien translates the most recent findings from neuroscience to **leadership development trainings, impulse speeches and leadership retreats**. She uses her expertise in the domain of applied neurosciences to give powerful and inspiring insights into daily behavior and decision making, with the aim to maximize the true potential of the participants and increase their agility in a world where change is the only constant.

- **Founder** of Science & Leadership Academy (www.science-and-leadership.com)
- **International speaker** for business events and conferences
- **Expert applied neurosciences** to leadership trainings, keynotes and retreats
- **Bestseller author** of the book 'How the brain reaches a peak performance', published by the F.A.Z. and 'The Pilgrim Who Trained her Monkey'.
- Selected **TEDxTalk Speaker & GedankenTanken (Greator) Speaker** 'Hack your brain'
- Ph.D. Neuroscience and Master Economics (K.U.Leuven, Belgium)
- Senior Faculty **several top business school world wide**
- **Best Teaching Award** for 'High Performance Teams' and 'Digital Leadership' of **MBA Programs** Goethe Business School
- **Best workshop** 'NeuroLeadership' (Summer University, ICF)
- **Qualified** facilitator for the **LEGO® SERIOUS PLAY METHOD®** (Team Building, Change Management, Corporate Identity Development)
- **Publications in high impact A-journals** (e.g., Behavioral and Brain Sciences)
- **Free time runner and climber**

Speaking topics, seminars, leadership retreats – neuroscience to business:

- Wise leadership: leading with the brain in mind
- Digital leadership: Leading in times of change and digitalisation
- Tackling the biased brain: right and fair decision making
- Creation of high performance teams
- Leading diversity: Decreasing unconscious bias and leading diverse teams
- Female and Inclusive Leadership (for all)

OPENING KEYNOTE. HACK YOUR BRAIN – UNLOCK YOUR UNIQUE POTENTIAL (ENGLISH)

How can you unlock your unique potential so you can become the best version of yourself? Neuroscience provides answers. In this talk, Dr. Karolien Notebaert will shed light on how the brain processes information and why we see out there is a direct result of who we are right now. The audience will learn what a natural mental performance and unlocking potential in the brain truly means. We all are gifted with a unique combination of talents, skills, interest and strengths. The secret lies in understanding how we can access our unique potential, especially in challenging situations. In this context, self-regulation plays a significant role. Although self-regulation is known as a personality trait we are born with, luckily, it also is a skill that can be trained. Self-regulation will

be interactively introduced as a key to naturally become the best version of who we are – and eventually create a better version of human kind.

Key take-aways:

- Information processing in the brain: What we see out there is not what is out there. What we see out there, is who we are.
- Performance stands for our own potential minus our internal interferences. Internal interferences can be the result of challenges, stress or feelings of fear and insecurity. They secret lies in understanding how we can reduce our own interferences.
- Self-regulation is a key competence to master yourself and the rest of the world. Self-regulation is a significant predictor of our success, both in private and professional life.

SPECTROM-an online training programme to reduce the overmedication of people with intellectual disabilities.

Professor Shoumitro (Shoumi) Deb, MBBS, FRCPsych, MD and Miss Bharati Limbu, BSc

Imperial College London, UK.

Background People with intellectual disabilities (PwID) are at a higher risk of developing challenging behaviours (CB). CB poses a major management problem and may lead to the use of restrictive practices such as physical restraint and inappropriate use of medication. Despite the poor evidence for the effectiveness of psychotropic medications in managing CB, they are widely used among pwID (50%-63%).

Methods We have developed a training programme, SPECTROM for support staff using Experience-based co-design (EBCD) method that includes all stakeholders equally from the outset. We carried out four focus groups; two with support staff only (n=8) and two with service managers and trainers (n=8), and a one-day co-design event (n=30). For field-testing, the SPECTROM training was delivered to 20 trainees. Changes in staff attitude to CB and psychotropic knowledge were assessed by analysing pre-, and post-training data from the Management of Aggression and Violence Attitudes Scale (MAVAS) and psychotropic knowledge questionnaire. A semi-structured interview and a feasibility questionnaire were used for process evaluation.

Results SPECTROM (<https://spectrom.wixsite.com/project>) has (a) web-based training, consisting of 14 modules, and internal and external resources, and (b) face to face training, consisting of medication/STOMP and alternatives to medication core modules. There was a significant improvement in the attitude to 'medication management' subscale score ($p<0.05$) and participant's knowledge

of psychotropic medications ($p=0.006$). Qualitative analysis showed the training helped to a) change staff attitude toward CB and its management, b) improve staff self-reflection and knowledge, c) improve the support provided to pwID, and d) feel empowered.

Conclusion SPECTROM is a useful training that helps to change the support staff's attitude toward CB and improve their knowledge of psychotropic medications.

From science to practice Using a coproduction method, we have developed an online freely available training programme for support staff which should help to reduce the overmedication of pwID.

New insights on psychopathological assessment in persons with intellectual disability and low-functioning autism spectrum disorder

Marco Bertelli

Intellectual disability (ID) and autism spectrum disorder (ASD) are associated with a broad vulnerability to concomitant health issues, especially psychiatric disorders, with a prevalence up to four times higher than in the general population. ID and ASD often co-occur, and their differentiation may be difficult, especially in the context of increasing severity of cognitive impairment.

In persons with ID and/or low-functioning autism spectrum disorder (LF-ASD) the presentation of psychopathological symptoms and syndromes can considerably vary from that of the general population, for a number of reasons including cultural factors, cognitive and communicative impairments, developmental peculiarities, and neuroautonomic vulnerability. Psychiatric symptomatology can present scarcely defined, chaotic, mixed, intermittent, atypical or masked. Even key elements of some syndromes, such as delusions, hallucinations or suicidal ideation, are often very hard to recognize, especially in persons with low or absent verbal communication skills, who may only be able to express themselves through changes in behaviour.

Some problem behaviours have been identified as symptoms, or groups of symptoms, specific to some psychiatric disorders (PD), taking the name of "behavioural equivalents" (BE), especially in persons with low functioning and low adaptive skills. These BEs have to be carefully distinguished from other problem behaviours, based on some characteristic, such as onset, development, maintenance and extinction, especially in respect to other concurrent possible symptoms of a PD. Some BEs have been included in the last adaptations to ID/LF-ASD of the DSM and ICD diagnostic criteria for the general population. Instrumental assessment can usefully support clinicians in the identification of BEs, although available tools show considerable differences in structural and psychometric characteristics.

In the present talk a new comprehensive set of tools is presented, whose automatic score reporting includes odds indicators of behavioural equivalence for every significant behavioural change, specifically “relative syndromic weight”, “syndromic specificity”, and syndromic clinical relevance. This new tool battery, called SPAIDD (Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities), has been designed to meet all the different practical needs related to every phase of the clinical intervention (general psychopathological screening, diagnostic categorical specification, dimensional diagnosis, and symptoms monitoring) and can be used by mental health professionals with different background and by the whole multidisciplinary team working with people with ID and LF-ASD. Authors of this tool system also tried to overcome the other main limits of previous tools, such as impossibility of being used across the range of cognitive and communication impairments, misalignment with DSM or ICD, lack of some main symptoms or syndromes, lack of chronological criteria, and high time expenditure.

The increasing availability of personal digital devices equipped with sensors offers new opportunities to continuously and passively measure human behavior in relation to mental health states and environmental context and may help to increase our understanding of behavioural symptoms of different PD.

Simple and to the point:

- People with intellectual disability and autism often have additional mental health conditions
- These show up differently than in the normal population and are often difficult to detect
- Especially people with autism who do not speak can be mentally ill without being noticed
- The combination of different problematic behaviors is typical for different mental conditions
- The *Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities* (SPAIDD) is a combination of different scales for status and progression diagnosis
- In addition, personal digital devices with sensors can be used to improve diagnostics

Living with Autism – an encouragement

Christine Preißmann

What does it mean for a person to get diagnosed with autism and to be on the spectrum?

How do characteristic features become noticeable, what is the effect of the diagnosis and what measures can help to cope - also in adulthood?

These and many other aspects will be discussed in Christine Preißmann's presentation. Being both a physician and diagnosed with an autism spectrum condition herself, she reports from two different perspectives. Some things can be better understood if one knows them from one's own experience, and many forms of help can be tailored more precisely if autistic people themselves are asked about their needs.

In her publications, the speaker gives a voice to a broad spectrum of people with autism, who describe in an intelligent and reflective way how their life looks like, what is important to them, and what may help them. Among professionals, it is becoming increasingly clear how important it is to consider these personal experiences. Professionals in education, therapy or medicine might be better at describing the professional side, but people with autism are experts in their own experiences and ideas - and finally, when we combine both, we can optimize the understanding of autism spectrum disorders and the development of appropriate assistance for the people affected.

Christine Preißmann is a general practitioner and psychotherapist, and is on the autistic spectrum herself. She works part-time in a psychiatric clinic, writes books for professionals as well as for patients and relatives and gives lectures on autism. She moderates a self-help group for young adults with Asperger syndrome in Frankfurt and is a member of the board of Autismus Deutschland e.V.

Simple and to the point:

- Christine Preissmann is a physician and is herself on the autism spectrum
- She reports on how the diagnosis of autism affects those concerned and their environment
- Many services can be better tailored if autistic people are included in the planning and if they are asked about their needs

Focus on the brain: How individual genes, prenatal epigenetic characteristics and early interaction experiences shape resilience and risk

Nicole Strüber

The individual genetic makeup of a person, their prenatal programmed epigenetic characteristics and early interaction experiences influence the chemistry and the neuronal networks in the brain. This in turn affects how people deal with high demands later in life, how effective they are in regulating their emotions, and whether they feel comfortable in relationships.

Numerous research results show that traumatic experiences can shape the development of the brain in such a way that the risk of developing mental illnesses is increased. Secure attachment experiences, on the other hand, can create resources that help people to deal with later traumatic or chronic stress experiences appropriately. Secure attachment experiences are therefore the basis for resilience. Later in life, psychotherapy, but also other activities, can reduce the influence of an unfavourable early imprint on behaviour through effects on the brain.

Simple and to the point:

- Next to genetic disposition, early interaction experiences influence brain development
- The early stage of development affects emotion regulation, relationship skills and social well-being in later life
- Traumatic experiences can shape brain development - with an increased risk for mental illnesses
- Secure attachment experiences are the basis for resilience in dealing with later stress experiences
- Psychotherapy and other activities can reduce the impact of an early imprint on the brain

Alzheimer's disease in Down syndrome - from understanding pathology to prevention

André Strydom

Adults with Down syndrome (DS) have neuropathological features identical to individuals with sporadic Alzheimer's disease (AD) and this discovery played an important role in the identification of the amyloid precursor protein gene on chromosome 21. Individuals with Down syndrome have a lifetime risk for dementia in excess of 90% and DS is now acknowledged to be the most common genetic cause of Alzheimer's disease, but they are often excluded from AD medication trials.

This keynote will cover aspects of Alzheimer's disease in Down syndrome including outcome measurement issues pertinent to prevention trials, and consider the methodological issues and potential targets for trials to prevent or delay AD in DS.

Simple and to the point:

- People with Down syndrome have a high risk of developing Alzheimer's dementia
- This group is rarely included in clinical studies of Alzheimer's disease

- Methodological issues and goals for future studies are discussed to prevent or delay Alzheimer's disease in people with Down syndrome

From neurodiversity to neuroharmony: intellectual disability, autism and happiness

Peter Vermeulen

All the research and all the information about how different and unique people with autism and/or an intellectual disability are, has made us forget that they are not only different, but that they share more than we think with all the other people, especially when it comes to basic needs such as happiness. Accepting neurodiversity is fine, but it emphasizes the differences between people. While it is a big step towards more acceptance of autism / intellectual disability as one of the many ways a brain can operate, it is only the first step in our commitment to a better world and more well-being for people with neurodevelopmental challenges. We should also focus on what connects people with intellectual disability/autism with the rest of the human species: the pursuit of happiness.

Happiness has received little attention in the field of autism spectrum disorders/intellectual disability. Outcome and effect studies, for instance, rarely take emotional well-being as a desired outcome. And when the focus is on well-being, it is often from a negative perspective, namely the lack of well-being and quality of life in people with a disability. It is time to take a U-turn in our approach and change from an exclusive focus on what makes people with autism and/or intellectual disability so different and from a negative, clinical and medical approach of happiness in people with disabilities (lack of distress) towards a shared and positive focus (we all want to be happy). In other words: let's move from neurodiversity to neuroharmony.

In the presentation we will explore how we can increase the well-being of people with ID / autism throughout the lifespan, from early childhood into late adulthood. We will explore ways of assessing the well-being and how to increase it. We will talk about good feeling but also about life satisfaction and contentment as main sources of emotional well-being. And we will illustrate with the story of Thijs, a boy we diagnosed back in the eighties and now a happy adult. His story will show how we can move from neurodiversity to neuroharmony, an inclusive world where people with and without disabilities are living in harmony.

Simple and to the point:

- The pursuit of happiness connects people with intellectual disability/autism with the rest of the human species

- In research the focus on emotional well-being is rare. It often focusses on negative aspects, i.e., the lack of quality of life
- A shared and positive approach with a change from neurodiversity to neuroharmony is desirable
- Ways of assessing and increasing the well-being in people with intellectual disability/autism will be discussed
- The case example of a young boy moving to adulthood will show how people with and without disabilities may live in harmony in an inclusive world

Meet the Expert

Psychotropic drug use in intellectual disability and low-functioning autism spectrum disorder: Who, What, When, How, and Why?

Marco Bertelli

Intellectual developmental disorder (IDD) and low functioning autism spectrum disorder (LF-ASD) include a wide range of lifelong neurobiological conditions with different clinical features and vulnerabilities, which imply specific psychopharmacological strategies. In the last years many studies are increasingly targeting specific genetic syndromes, such as Fragile X syndrome, Prader-Willi syndrome, Rett syndrome, tuberous sclerosis, and Phelan-McDermid syndrome. Many other aspects, such as co-occurring physical and mental health issues, problem behaviors, or quality of life further enlarge the need of treatment differentiation up to the individual level, entailing tailored psycho-pharmacy and participation of the multi-professional social and health care team.

The correctness and precision of psychiatric diagnoses is a fundamental prerequisite for an effective therapy, especially when targeted at behavioral symptoms, such as irritability, aggression, self-injury, or temper tantrums. If challenging behaviors have not been proven to be symptoms of a psychiatric disorder, their management through psychotropic drugs should be considered only after other non-pharmacological interventions have failed. Drugs should be used at the lowest possible dose and for the minimum duration, with non-medication-based management strategies and the withdrawal of medication being considered at regular intervals.

The most commonly prescribed psychoactive drugs are antipsychotics, especially second-generation antipsychotics (SGA), followed by antidepressants, antiepileptics/mood stabilisers and stimulants. Evidence on efficacy, dosage and safety on adults is scarce and derived mostly from naturalistic studies or case reports, with a main focus on identification of side effects and discontinuation

rate. Placebo-controlled or active-controlled studies are limited, with small sample size. Some SGA have been shown to be useful on some behavioural symptoms. Specifically, risperidone and aripiprazole are increasingly reported to be effective on irritability marked by aggression, self-injury, and severe tantrums. More limited data are available for other SGA who are frequently used in daily practice, including clozapine.

Attention deficit and hyperactivity disorder medications may be effective for counteracting the additional features of hyperactivity and short attention span. Antiepileptics, mood stabilizers and selective serotonin reuptake inhibitors have shown promising results, but evidence seems to be even lower and indications even less precise than for the other classes. Some newer compounds, such as asenapine, cariprazine and vortioxetine, have shown few side effects and present a receptor binding profile which is suitable with the characteristics of a large part of this special population.

The usefulness of psychotropic drug use should be judged in terms of effectiveness rather than efficacy (on target symptoms) and safety, with the former including the capability to keep the patient on treatment for the right time and the impact on generic quality of life.

Simple and to the point:

- In cases of intellectual disability and low-functioning autism, a tailored therapy with psychotropic drugs can be useful
- Valid diagnostics and the involvement of the multiprofessional social and health care system are the basis for effective pharmacological treatment
- Medication of challenging behaviour should only be used when non-pharmacological strategies fail, and at the lowest possible dosage for the shortest possible duration
- The most commonly prescribed psychoactive medications are second-generation antipsychotics and antidepressants
- Data on the efficacy, dosage and safety of antidepressants and mood stabilisers in people with intellectual disability is sparse; the use of other groups of medication will be discussed

In psychopharmacological treatment, it is generally important to consider the necessary duration of treatment and the effects

Blind spots! A look at some of the outcomes of the Norwegian reform in service systems for persons with intellectual and developmental disabilities

Karl Elling Ellingsen

Norway played a lead role in deinstitutionalization by reforming services in 1995, and received appreciation from many countries as well as nationally. The overall goal is improving quality of life, inclusion, participation, and to ensure the well-being for all persons with intellectual developmental disability in Norway. By aiming high, the expectations equally are high.

The presentation will give insight in how Norway is organizing and carrying out services for persons with IDD, with a special focus on mental health, how the society in general is orientated towards inclusion, and what the realities are described through research.

Simple and to the point:

- Norway played a leading role internationally in the deinstitutionalisation of people with intellectual developmental disabilities
- Quality of life, inclusion and participation played a central role in the reform of care systems
- Organisational structures, social impact, mental health and health services research will be addressed in the lecture.

Lessons from a Global Pandemic: What have we learned?

Jeanne Farr

The pandemic required creative approaches to meeting the support needs of individuals with intellectual disabilities. Service and clinical treatment approaches had to quickly adapt in response to the rapidly changing environment.

Interviews with clinical professionals and service providers from the following 20 countries: Afghanistan, Australia, Canada, China, Croatia, Denmark, Finland, Germany, India, Israel, Japan, Kenya, Mexico, Netherlands, Paraguay, Philippines, Slovakia, Spain, Uganda and US.

The interviews will elicit specific strategies these professionals used to focus on supporting the quality of life and the mental health and wellbeing of the people they support.

To learn from clinical professionals and service providers from around the world regarding what they did to pivot and respond quickly to the unplanned circumstances we all faced in our work with individuals with intellectual disabilities and mental health challenges.

To learn what strategies worked and what did not.

There is a rich source of collective wisdom from our fellow professionals around the world and we can learn a great deal from one another. This exploration gives us a glimpse into the larger world of committed professionals dedicated to

supporting the health and wellbeing of people with intellectual disabilities during extraordinary times.

In presenting the data from the surveys, we will learn from our global community of practitioners and have the opportunity to further explore or adapt new ideas to our own framework for treatment and service provision.

Simple and to the point:

- Support services need to adapt with regard to the new challenges posed by the pandemic
- Strategies have been collected from professionals around the world
- It is important to learn which strategies have worked and which have not
- International exchange helps in the development of new strategies

Video-feedback intervention to support parents with intellectual disabilities

Marja W. Hodes

More and more persons with intellectual disabilities are starting a family of their own, often based on the intense desire to become a parent. However, when we are looking at the choice to become a parent, persons with intellectual disabilities encounter many challenges. The parties to the United Nations Convention on the Rights of Persons with Disabilities (2006) have seen it as pertinent to affirm the right of persons with disabilities to start a family and calls for appropriate assistance to persons with intellectual disabilities in the performance of their child-rearing responsibilities.

Several studies underpin that parents with intellectual disabilities (ID) are able to learn parenting skills and can improve parenting behaviour. Three important factors are contributing to this result: parents are daring to ask for support and accept the support offered; parents are provided with effective parenting support programs and parents have access to a supportive social network.

In the Netherlands from 2008 until 2017 the consortium 'What works for parents with intellectual disabilities' (VU – Amsterdam) conducted research based on these protective factors. An evidenced based video feedback intervention for the typical population, based on attachment and coercion theory, was tailored and tested for parents with ID (VIPP-LD) in a randomized controlled trial and demonstrated to alleviate parenting stress for the whole group and the group parents with low adaptive functioning improved in parenting behavior. At the moment this intervention is becoming implemented. Professionals are in training and start to support families headed by parents with intellectual disabilities in settings where families live independently in their own houses and in families living in special family support homes.

In this presentation we will show how the results of the research done is transferred to practice. We take you into the process of implementation, the way how to introduce this evidenced based intervention as a valuable treatment in families headed by parents with ID, the way how to get government interested, involved and supportive (including funding) and the training of professionals. We take you to the best practices but also to the lessons learned. And last but not least we will share the stories of parents themselves, the way they feel supported in their parenthood.

Simple and to the point:

- Many people with intellectual disabilities have the desire to become parents
- People with disabilities have a right to start a family and to appropriate support in raising children
- Starting a family can be successful if there exist support programmes, if parents dare to ask for and accept help, and if there is a social network available
- A large study in the Netherlands has shown how a video support programme reduced parental stress and helped parents with intellectual disabilities to cope better with their children
- The implementation and funding of the programme are described and the parents themselves also have their say with reports on their experiences

Emotional development in persons with intellectual disability

Filip Morisse and Leen De Neve

Participants can meet experts who have been working with the developmental approach for decades. They use the assessment of emotional development in their mental health practice for people with intellectual disability.

The experts have founded the NEED-group (Network for Emotional Development) with other European colleagues and conduct research on this issue. Participants can discuss the process of bringing emotional development from theory to practice with the experts.

State of the Art

Building resilience: researching the practice of Mindfulness and Acceptance and Commitment Therapy with family carers of adults with learning disability and challenging behaviour

Tina Cook

This presentation offers insights into how science and practice, in the form of participatory health research, came together to understand the basis for

effective ways of engaging family carers in Mindfulness and Acceptance and Commitment Therapy.

In the UK it is recognised that family carers of people with learning disability and challenging behaviours play a vital role in ensuring the health and welfare of their relative. It is acknowledged, however, that services to support family carers are scarce with more being provided by local self-help groups and charities than the NHS. The impact of different types of support for families is rarely researched.

The aim of the participatory research project known as Family Based Positive Support (FaBPoS) was to better understand what might enable family carers to maintain resilience in the face of ongoing and new challenges encountered in their long-term caring roles. Participatory health research involves all those whose lives or work are affected by the research, in the research - not as subjects but as active participants. Those involved have agency in shaping the research process, the understandings and new knowledge being developed, and the application of that new knowledge in practice.

The project revealed how the knowledge of the seldom heard (family carers), alongside the knowledge of those usually defined as the experts (clinical psychologists), produced surprising outcomes. Not only did the participatory processes adopted have an impact on the resilience of family carers but it rippled out to affect the person they cared for, and significantly, the professional practice of clinical psychologists involved in the research. FaBPoS also emphasised the value of including diverse forms of expertise for creating meaningful change.

Simple and to the point:

- Family carers of people with learning disability and challenging behaviours play a vital role in ensuring the health and welfare of their relative
- Services to support family carers are scarce with more being provided by local self-help groups and charities
- Family Based Positive Support (FaBPoS) is a UK-based participatory research project and aims to support family carers in their long-term caring role
- The participatory processes had an impact on the resilience of family carers, affected the person they cared for, and significantly, the professional practice of clinical psychologists involved in the research

Mental health of deaf people with intellectual disabilities

Johannes Fellingner

One out of five deaf people has special needs, mainly intellectual disabilities (ID). Almost half of the population with special needs in learning and mobility has hearing problems, which often stay undetected. Many of them have no access to sign language and live quite isolated in hearing and speaking environments, either with their relatives or in institutions for people with ID. Miscommunication is frequently the reason for challenging behaviour in this vulnerable population.

In addition to existing literature, a thorough description of a deaf population with ID (N=61) gives insight into different aspects of their mental health. This includes analysis of their cognitive, language and socio-emotional development, their clinical diagnoses and their quality of life.

When providing support and care for individuals who are deaf and have an intellectual disability, various aspects have to be considered in order to guarantee their human rights in communication and social participation. A model of a therapeutic community, established to meet the specific needs of the target group is presented.

Simple and to the point:

- Many people with an intellectual disability also have hearing problems, which often stay undetected
- Various aspects of mental health of deaf people with an intellectual disability are presented, including social-emotional development and quality of life
- Based on the model of a therapeutic community, appropriate support and care to meet the specific needs of the target group will be discussed

Biology of dissociation: current findings from stress research

Kim Hinkelman

The term dissociation describes an interruption of the normally integrative functions of consciousness, memory, identity or perception of the environment. Dissociative phenomena are quite common and also occur in everyday life. The development of dissociation is multifactorial, i.e. caused by an interaction of biological, life and learning history as well as genetic factors.

Dissociative symptoms are multifaceted and range from feeling confused to the loss of pain sensation and the ability to act. According to ICD-10, functional neurological symptoms such as movement disorders or seizures are also counted among them. However, "psychological" dissociative symptoms are often reported in the context of traumatization, so that a connection with the stress response is obvious.

This lecture will use examples from animal and human studies to provide an overview of various neurobiological factors that play a role in dissociation, as well as illustrating possible mechanisms of dissociation on the basis of findings from stress research.

Simple and to the point:

- In dissociation, important functions such as consciousness, memory, self-perception and perception of the environment are interrupted
- Dissociation can feel like “being beside oneself”, but can also be associated with complete inability to act
- The reasons for a dissociative state are manifold, psychological dissociative symptoms are usually stress reactions and associated with traumatization
- Studies on animals and humans as well as stress research give an overview of neurological factors and mechanisms involved in dissociation.

Enhancing the wellbeing of people with severe intellectual disability and complex needs

Chris Oliver

A substantial body of research has identified the importance of environmental influences on the behaviour and wellbeing of people with severe intellectual disability and complex needs. This research has generated the prevailing biological, psychological and social interventions that emphasise change in the environment and, by implication, a minimal role for individual difference in causal models of understanding behaviour and wellbeing.

A second line of research has demonstrated repeatedly the strong links between the cause of intellectual disability, behaviour and aspects of wellbeing. For example, genetic and individual differences are associated with the developmental trajectory, prevalence, and presentation of sleep problems, anxiety, self-injury, sensory sensitivity and social behaviour.

Importantly, influences on behaviours and wellbeing accumulate and interact in different ways across numerous specific genetic causes and can provide insight into the nature of complex needs across all people with severe intellectual disability. Recognising that both environment and individual differences and their interactions underpin behaviour and wellbeing can extend the targets for support, help focus environmental change, and enhance the likely effectiveness of interventions.

Simple and to the point:

- The influence of environment on the behaviour and well-being of people with severe intellectual impairments is widely recognized.

- There are strong links between the cause of the intellectual disability, the person's behaviour and their wellbeing that are equally important but often overlooked.
- It is important that individual differences and their interaction with environmental causes are considered for creating supportive and effective interventions.

Orals English and German Online and Offline

Topic: Inclusion Society and Community

A study of parental perspectives on tutoring sessions for children with disabilities during COVID-19

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1Department of Psychology, University of Prishtina, Hasan Prishtina,

2Utrecht University, Degree in Pedagogical Sciences

Background The COVID-19 pandemic along with pre-existing conditions and the lack of support amplified the challenges of children with disabilities and their parents by aggravating their mental health problems and deepening educational inequalities.

The aim of the current study was twofold: to explore the challenges of children with disabilities and their families during the COVID-19 pandemic in Kosovo, and examine the impact of tutoring sessions and socio-emotional support on children with disabilities and their families implemented as a project of the Department of Psychology.

Methods Semi-structured interviews were conducted with 20 parents of children with disabilities upon the end of the tutoring programme implemented.

Results/Aims The findings revealed that children with disabilities faced numerous challenges while engaging in the school's online learning during the pandemic, including lack of access, inadequate online teaching and trouble getting used to the online format. These factors affected their moods and increased their parents' stress levels. The parents were overwhelmed and dissatisfied with their children's academic achievements through online schooling.

The individual tutoring sessions between university students and the children had positive effects on the children by improving their moods, attitudes towards learning, and academic achievements; and on their parents by decreasing their stress levels and relieving them from being overwhelmed by their children's educational engagements. Parents also report of empowerment of their children.

Conclusions/ From Science to Practise Tutoring sessions involving individualised teaching are reported beneficial to children's academic achievement and family wellbeing. School-home partnership is also considered crucial to tutoring and online learning for enhancing child academic achievement and socioemotional development.

Keywords COVID-19, Children with disability, Tutoring programme, Family Support

Some Aspects of Community Participation of Adults with Psychosocial Disabilities

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Inclusive Education and Rehabilitation, Zagreb, Croatia. ²Ministry of Labour, Pension System, Family and Social Policy, Zagreb, Croatia.

Background A large number of persons with psychosocial disabilities continuously experience some form of social isolation. In response to this challenge, community participation has become a primary goal of mental health policies and services. Community participation is an important predictor of quality of life and recovery of adults with psychosocial disabilities, therefore it should be subject of research.

Methods The research involved 80 persons with psychosocial disabilities in community-based settings (N=40) and state institutions (N=40). Data were collected with Community Participation Scale and Demographic Questionnaire.

Results/Aims Research aim was to investigate aspects of community participation of persons with psychosocial disabilities. Obtained results confirm that persons with psychosocial disabilities participate in a very limited range of community activities. The most frequent activities among persons with psychosocial disabilities in community-based settings are: going to the store, cafe, pharmacy, hairdresser, visiting a friend and going out with friends, while only a small number of persons go to concerts and visit places of worship. Persons from institutions most often go to the store and cafe, while they very rarely participate in other activities in the community.

Conclusions Although this research confirmed that adults with psychosocial disabilities in community-based setting significantly more participate in community activities, the fact that both groups very rarely participate in activities such as recreational activities, theater/cinema, sports events, spending the night with families etc. is worrying. Limited range of community activities in which they participate is a challenge for support services.

From Science to Practise Based on the obtained findings, community activities in which there is no participation will be included in the support services programmes.

Keywords community participation, psychosocial disabilities, recovery;

Befriending in adults with intellectual disability and depressive symptoms: A pilot trial

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Background No studies have examined whether befriending improves symptoms of depression and social outcomes in people with Intellectual disability. The aim of this study was to assess the feasibility and acceptability of a future randomised controlled trial (RCT) of one to one befriending in people with Intellectual disability and depressive symptoms.

Methods Participants were adults with mild or moderate Intellectual disability with a score on the Glasgow Depression Scale for People with Learning Disabilities (GDS-LD) of 5 or above and were randomised to either the intervention arm or the control arm (usual care). Participants in the intervention arm were matched to a volunteer and were required to meet once a week for 6 months. Volunteers received training and supervision. Two community befriending schemes were responsible for delivering the intervention. The main outcomes were feasibility of recruitment (target n=40), retention rate of participants, adherence (minimum 10 meetings) and acceptability of the intervention, and changes in depressive symptoms (assessed at baseline and 6 months).

Results/Aims Due to challenges with recruitment, we only recruited 16 participants with Intellectual disability and 10 volunteers. Six participants were matched with a volunteer and no participants dropped out (except 2 volunteers). There was good adherence (mean 11.8 meetings). Befriending was considered acceptable but modifications were suggested. The GDS-LD score was lower in the intervention group compared to the control group (adjusted mean difference: -4.0; 95% CI: -11.2 to 3.2).

Conclusions There were challenges in recruitment and therefore a large scale RCT is not feasible.

From Science to Practise Befriending could be beneficial for people with ID but requires further evaluation.

Keywords Intellectual disability, befriending, depression, pilot, randomised controlled trial

Topic: Communication

Assessing Conversational Skills of Adolescents and Young Adults with Developmental Disabilities

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Background Social communication difficulties of adolescents and young adults with Developmental Disabilities (DD) can significantly interfere with their full participation in social activities in major life contexts (Carter et al., 2014). The increased demand for social conversation during adolescence may widen the gap between this population and their typically developing peers, contributing to social exclusion and isolation (Bambara, Cole, Kunsch, Tsai & Ayad, 2016).

Methods The study aims to extend previous studies' findings to develop a model to describe typical taxonomies of conversational exchanges. Starting from verbal operants' function, specifically considering speaker-listener exchanges, we aimed to develop a useful tool for assessing adolescents and young adults with DD's conversational abilities. The dependent variables investigated were initiations and responses. For each variable, we defined the different functions based on Bambara et al. (2018): request, request for information, comments, obligatory answers.

Results/Aims The assessment will be the starting point for developing highly individualized interventions to improve the conversational skills of young people and adults with DD. For example, practitioners can use scripts for young people who show difficulty in initiating a conversation or asking relevant questions to the other person on the topic of conversation. Other behavioral strategies, such as role-play, can be used to encourage young people in sustained conversation.

Conclusions Conversational skills are essential for interactions. The proposed model can help professionals develop individualized interventions to address specific conversational difficulties of adolescents and adults with DD.

From Science to Practise Adolescents and adults with DD can benefit from this study, as improved conversational skills increase social contexts' quality of life and opportunities for inclusion.

Keywords Conversational skills, Social Skills, Developmental disabilities

Topic: Autism Spectrum Disorder and Related Developmental Disorders

Autism screening in adults with intellectual disability and hearing loss: validity of the Diagnostic Behavioral Assessment for Autism Spectrum disorders-Revised and Pervasive Developmental Disorder in Mentally Retarded Persons

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Background There is a lack of autism screening instruments for adults who are deaf or hard of hearing (DHH) and have intellectual disability.

Methods This study examines the diagnostic validity of two autism screeners developed for adults with intellectual disability., the Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS) and the Diagnostic Behavioral Assessment for Autism Spectrum disorders-Revised (DiBAS-R) in 56 DHH adults with intellectual disability., 9 of whom meet criteria for autism.

Results/Aims Using minimal adaptations regarding item interpretation, both screeners showed good diagnostic and high convergent validity. Items probing for difficulties in reciprocal social interaction and restricted interests, but not ritualistic and sensory seeking behaviors, were highly discriminant between individuals with and without autism.

Conclusions These data suggest that the PDD-MRS and the DiBAS-R with appropriate adaptations are adequate autism screening tools in DHH adults with intellectual disability.

.From Science to Practise The PDD-MRS and the DiBAS-R with appropriate adaptations are adequate autism screening tools in DHH adults with ID.

Keywords Autism Spectrum Disorders, Autism Screening, Deaf and Hard of Hearing, Sensory Impairment, Intellectual Disability, Adults

Topic: Challenging Behaviour

Autonomy restrictions & custodial measures from the perspective of adolescents with intellectual disabilities

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Background The appropriateness of and justification for custodial measures in inpatient institutions of disability care is an emotive issue. It creates a number of ethical dilemmas due to its massive interference with a person's fundamental rights. The research project „*Challenging behavior in the context of inpatient*

institutions of disability care – autonomy restrictions and custodial measures from the perspective of children & adolescents, parents and staff" (2017-2021) aims to explore experiences of different actors, who are involved in applying custodial measures.

This conference paper focuses on the perspective of children and adolescents affected by the use of custodial measures.

Methods Eighteen children and adolescents with so-called intellectual disabilities living in residential settings were interviewed about their experiences with custodial measures. Nonverbal response offers were made when needed. Qualitative content analysis was used to analyse the interviews.

Results/Aims Overall, the interviewed children and adolescents perceived the application of custodial measures (e.g. room confinement, restraint) negatively. An experience of non-alternatives, shame and resignation was evident throughout the interviews. Furthermore, forms of self-pathologization occurred. A lack of possibility to process and reflect experiences of custodial measures in everyday life became evident.

Conclusions Children and adolescents who are affected by the use of custodial measures experience an increase of feeling powerless. They should be included in the reflection and reduction of custodial measures. Occurred incidents and individual plans of response should be discussed with affected children and adolescents themselves

.From Science to Practise As a result of the research project (picture based) material will be developed, which can be used for the participatory reflection of custodial measures.

Keywords Autonomy restrictions, custodial measures, so-called intellectual disability, subjective experience

Effect of the use of an iPad on the attention span of a child with Smith Magenis Syndrome: a single case study

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Background To assess the effectiveness of iPad use on the attention span of a child with Smith Magenis Syndrome (n=1), compared to attention span while working on the same tasks manually.

Methods An AB design with a baseline and an intervention phase was used. Three manual tasks were chosen for the baseline, which matched the participant's intellectual age by the Early Intervention Method: a jigsaw puzzle

(6 pieces), a shape sorter, and matching pictures. These same tasks were performed on an iPad during the intervention phase.

Results/Aims iPad use led to a 45% decrease in the number of total distractions. The effective working time improved by 8% and showed a more consistent range compared to working on tasks manually.

Conclusions In this single case study the participant showed that in his case iPad use can be effective in decreasing his distractions and therefore can improve his attention span. Enjoyment was higher while working with the iPad than performing tasks manually. This technology could therefore create more learning engagement for the participant, which could positively impact his behavior. Further research into iPad implementation for children with intellectual disabilities, poor fine motor skills, and/or attention deficits is needed.

From Science to Practise At a time when the use of a tablet has become an indispensable part of daily life, both for pleasure and for cognitive purposes, our research shows that it is also an important device for people with IDD to explore.

Keywords iPad use, attention span, Smith Magenis Syndrome, intellectual disabilities, poor fine motor skills

Topic: Models of Care and Support

Building a community forensic service for people with intellectual disabilities and autism

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Background The Transforming Care Agenda is a national drive following an investigation into abuse of vulnerable individuals in institutional care in 2011. This aims to reform services for people with Intellectual and developmental disabilities (IDD) in England by building the right community support, with a target to reduce those in hospital by 50% by 2023/4.

Methods In April 2018 a community team was set up to support people with IDD and forensic needs in hospitals from Nottinghamshire, UK. This multi-disciplinary team worked with individuals in secure care with significant forensic needs, addressing factors to achieve a discharge from hospital. This required an intensive, collaborative approach with multiple agencies to create bespoke packages of care leading to sustained, safe community living.

Results/Aims We aided the successful discharges of 52% of long-term forensic patients from April 2018 to date. These predominantly include patients with

significant violence and sexual risk in their histories. These patients are managed under the Mental Health Act, Mental Capacity Act and Criminal Justice System legislations. Many have been in secure hospitals for up to 27 years, having previously been considered as indefinite hospital detentions; too risky for community living.

Conclusions Transforming Care has provided the resources for different ways of managing complex, risky patients in the community. This has been with a combination of high levels of support, professional expertise and monitoring to promote their quality of life, whilst managing high levels of risk in the least restrictive way. The service has provided evidence that such services are required to fulfill these aims.

From Science to Practice CFIDD has allowed complex people with IDD and significant risk histories to live sustainably and safely in the community, who would otherwise have been detained in hospital indefinitely.

Keywords

[Topic: Mental Disorders](#)

COVID-19 Impact in People With Intellectual Disabilities

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Background This study examined and assessed the difference in the stress impact generated by lockdown due to COVID-19 in people with intellectual disability using the Impact of Event Scale-Intellectual Disabilities (IES-IDs).

Methods This is a cohort study between two independent samples with intellectual disability before and during lockdown. The differences were analysed by Student's t test and Odds Ratio. NO COVID group (NCG) (n=64, average age 34, SD=9.4) and COVID group (CG) (n=152, average age 31, SD=8.7), over 18 years old. NCG (42%, borderline intellectual functioning; 37% mild intellectual disability; 20% moderate ID). CG (44% borderline intellectual functioning; 39% mild intellectual disability; 32% moderate intellectual disability).

Results/Aims Significant differences were found in the total of the scale with $d=2.03$ and $1-\beta=0.97$, with higher stress symptoms in the CG (NCG M=15.77, CG M=35.97). Furthermore, significant differences were found in all dimensions: avoidance, $d=1.94$ and $1-\beta=0.94$ (NCG M=5.89, CG M=12.42), intrusion, $d=2.10$ and $1-\beta=0.95$ (NCG M=5.73, CG M=13.48) and hyperarousal, $d=2.05$ and $1-\beta=0.95$ (NCG M=4.14, CG M=10.07). A higher risk of presenting

avoidant responses, intrusive thoughts and hyperarousal symptoms was found in the CG.

Conclusions Lockdown due to COVID-19 in the acutest period of the pandemic in Madrid has produced a clear stress in people with ID.

From Science to Practise If we assess the pandemic and the measures taken associated with it, we find a stressful life event that could be a traumatic event if the coping needs of the population with ID are not addressed.

Keywords Coronavirus, COVID-19, Intellectual disabilities, mental health

Topic: Empowerment and Independence

Daily time management and time-assistive devices for people with an intellectual disability

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Background People with an intellectual disability experience more problems with daily time management. However, assistive technology can reduce these negative consequences. This study examines the satisfaction and use of time-assistive devices and other types of support for improving the daily time management skills of people with a mild to moderate intellectual disability.

Methods In a Delphi study a list of time-assistive devices was examined during semi-structured interviews. Then, a modified form of this list was administered in online questionnaires for clients, family and for professionals in order to receive broader feedback from multiple participants. The participants' opinion was asked about the satisfaction and use of the various time-assistive devices and other forms of support.

Results/Aims The aim is to map the satisfaction and use of time-assistive devices to support people with a disability. Time-assistive devices such as weekly schedules, watches and alarm clocks were examined. The findings of this study were ranked. The ranking maps the most and least used time-assistive devices, the level of satisfaction with them and results in the five most used assistive devices and the devices with the most potential for implementation.

Conclusions The results indicate which time-assistive devices are actually used in practice and the level of satisfaction with these aids. The current research contributes to a better understanding of which time-assistive devices are most useful to support people with intellectual disabilities in practice.

From Science to Practise The research results provide an overview of the top five ranking of time-assistive devices that can support people with an intellectual disability in their daily time management.

Keywords Time-assistive devices, assistive technology, daily time management

The topic of health in the life stories of people with intellectual disabilities

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Background People with intellectual disabilities experience higher levels of ill-health at a young age. They are at an increased risk of chronic diseases, mental illnesses, obesity and cardiovascular disease. Therefore, they often have to deal with health-related issues in their everyday lives and overcome corresponding challenges.

However, due to limited cognitive and communicative abilities, people with intellectual disabilities are often assumed to feature low health literacy and thus low skills and resources in accessing and in dealing with health-related information.

As a result, caregivers and professionals in the institutional setting grant them only little scope for decision-making and action with regard to their own health. People with intellectual disabilities thus experience an increased dependence on others in a subjectively significant area of life throughout all phases of life.

Methods Biographical narrative interviews are conducted with people with intellectual disabilities living in residential facilities.

Results/Aims Since health-related decisions and actions entail considerable consequences for individuals, the project aims to elaborate the experiences of the people interviewed and their retrospective assessment of the (health-related) decision-making processes as well as the scope for action experienced throughout their lives.

Conclusions The interviews provide a first insight into how people with intellectual disabilities experience their scope for action and decision-making and to what extent health-related challenges influence their lives.

From Science to Practise Focusing on life stories allows people to look (back) on and reevaluate their own - sometimes challenging - experiences. The approach can promote well-being and act as an empowerment process at the same time. In addition, examining life stories can be an initial point for developing interventions e.g. in respect to educational opportunities.

Keywords Health literacy, life stories, self-determination, decision-making

[Topic: Profound Intellectual and Multiple Disabilities](#)

Design to implementation of technology-based interventions for visual (and intellectual) disability

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Background There is limited research related to communication assistive technology for people with disabilities is reported in peer-reviewed journals. Research publications available, specifically for intellectual disability, deaf blindness and visual impairment, often do not go beyond the prototype phase, impacting implementation strategies (Dyzel et al., 2020; Bakkum et al, 2021). The aim of this study is to present an example of the process of developing and implementing assistive technology using all Technology Readiness Levels, whilst remaining evidence based (Korving et al, 2020).

Methods The ‘Barti-mat’ - an interactive technology-based playmat, aimed to promote sensitive and responsive caregiver behaviour and increase happiness of children with visual- or visual- and-intellectual disabilities. A need related to caregiver-child interaction was identified, leading to the development of a proof of concept, prototype, evidence-based efficacy research and implementation. Each level was grounded on findings of previous results, feedback, and research.

Results The TRL stages were completed in the development of the assistive technology-based intervention. Throughout each stage relevant stakeholders participated, ensuring that the product remained relevant and effective. As a result, an evidence-based intervention was designed, developed, and implemented.

Conclusions Evidence-based assistive technology interventions within fields such as intellectual disability can be designed, developed, and implemented when relevant stakeholders and research are included in each TRL

From Science to Practice More sustainable in-depth research related to technology that goes beyond the prototype phase within diverse populations is needed. The involvement of stakeholders such as care- professionals, designers, and target population in the creation of technology-based products should be emphasized. ‘The Barti-mat’, can be used as a blueprint to promote future projects.

Keywords Intellectual Disability, Technology readiness, Assistive technology, caregiver-child interaction, caregiver sensitivity

[Topic: Health Literacy, Health Promotion, Health Education](#)

E-health, physical activity and intellectual disability – protocol for a pilot study

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Background There is a need to enhance physical activity (PA) and health situation in individuals with intellectual disability. E-health methods have been explored and found promising in individuals with IDs. Objectives are to assess feasibility of procedures for a covid-19-secure intervention for a planned complex randomized controlled intervention, as well as its effects on PA and secondary outcomes like motivation and self-efficacy in PA settings.

Methods Ten participants with intellectual disability aged 16-60, with low PA as well as carers and support persons will be invited to participate. The intervention involves a tailored e-health support, using smartphones or tablets to motivate by creating structure and increase predictability of physical activities. A qualitative interview will be held after the pilot study to assess experiences.

Results Recruitment will start in April 2021. Primary outcome will be steps per day (measured by Fitbit devices). Secondary outcomes are minutes of moderate PA, questionnaires on PA levels, goal attainment, mental health, PA related self-efficacy and social support.

Conclusions The goal is to enhance participation in PA in individuals with intellectual disability supported by implementation of motivating mobile health. The study will reveal experiences, feasibility, as well as success factors and estimations of effect sizes.

From Science to Practise Individuals with intellectual disability and society will benefit as it is important to improve health and wellbeing through enhancement of participation in Pas

Keywords Intellectual disability, physical activity, e-health

Physical and mental health in Intellectual Disability, preliminary data of a cross-sectional study

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Background Physical illnesses (PI) are reported to be more prevalent among adults with Intellectual Disability and low functioning Autism Spectrum Disorder (LF-ASD) than in general population.

Methods This cross-sectional study included 55 patients with Intellectual Disability living in a residential facility, mean age 56 years. PI were investigated with the Modified Cumulative Illness Rating Scale (CIRS), Barthel, Braden and Conley scales, while Psychiatric Disorders (PD) were assessed through SPAIDD (Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities) and CGI (Clinical Global Impression - Severity Scale). Statistical analysis was performed through Student's t-test and Pearson linear correlation test.

Results LF-ASD prevalence resulted to be higher among patients with severe ID. PI and PD were more frequent in those with co-occurrence of ID and LF-ASD. A statistically significant positive association between scores of CIRS and CGI-Severity was found (0.33). Barthel and Braden scales showed a significant correlation with CGI but with negative direction (-0.45).

Conclusions PI and PD seem to have reciprocal association in patients with Intellectual disability.

From Science to Practice Mental health practices for patients with Intellectual Disability and/or LF-ASD should increasingly address the cross-effects between mental and physical health.

Keywords Intellectual disability, Autism Spectrum Disorder, Physical health

[Topic: Emotional Development](#)

Influence of emotional development, mental disorders and problem behaviors in a population simple with ID

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Background: Mental disorders (MD) and problems behavior (PB) are more frequent in people with intellectual disabilities. Delayed emotional development (ED) plays an important role in MD and PB in people with ID, but publications on this area are still scarce. This is the first research in a Spanish population sample using the Spanish version of SEED scale, which studies a possible influence of the ED in the PB and MD in people with intellectual disabilities.

Methods: Seventy-eight adults with intellectual disabilities were included from the Hospitalization Unit for ID and MD (UHEDI), housings (Sant Ricard/Santa Anna) and occupational workshop in Parc Sanitari Sant Joan de Déu. MD were diagnosed follow DM-ID 2 criteria. PB was assessed by the application of ICAP scale and ED by the Spanish version of SEED.

Results/Aims:45 out of 77 (58,44%) of participants showed a MD and 24,35% of them an ASD. Participants with a more severe ID scored significantly lower in SEED ($p=0.0001$). Participants with PB scored significantly lower in SEED ($p=0.001$) and participants with ASD scored significantly lower in SEED ($p=0.001$). A statistical association between MD or epilepsy and ED was not found.

Conclusions: ED seems to be related with ID degree and with PB. People with ASD seem to have a lower ED level, but MD or epilepsy do not correlate in our sample with ED. The relationship between ED, PB and ASD is consistent with previous studies.

From Science to Practise:The understanding of ED and its relationship with PB and MD will promote new therapeutic approaches and therefore improve the quality of life of people with intellectual disabilities.

Keywords: Emotional Development, Autism, Psychiatric disorders, Problem behavior

Topic: Education and Employment

Needs of teachers regarding the education of children with learning difficulties
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Background While the number of children with learning difficulties (LD) increases, the teachers struggle to adapt their teaching methods to better suit all students' learning needs.

Methods Given the scarcity of resources and training in educating children with LD, especially in eastern European countries compared with more developed western European countries, this study aims at comparing Greece (N = 123, 95.7% females), Romania (N = 219, 91.3% females) and Belgium (N = 54, 77.8% females) in terms of their training needs concerning teaching children with LD.

Results Regarding training needs, the majority (over 80%) of teachers in all three countries want to receive training on cognitive education, collaborative strategies in interacting with parents, and challenging behaviours. Most teachers are worried that they do not have enough time to adapt their resources and prepare for their educational activity, and they are afraid LD will negatively change their children's perception of school.

Conclusions The teachers' training needs in all three examined countries are very high regarding children with LD, even though most respondents perceived the current quality of education relatively well. Their concerns reflect the preoccupation with optimizing teaching strategies to ensure a successful pedagogy.

From Science to Practice These preliminary results, coupled with the tendency to digitalize education, argue the need for an online training platform dedicated to teachers who interact with LD children.

Keywords learning disability, education, teachers, training needs, cognitive education

Topic: Models of Care and Support

Perspectives on the experiences of people with intellectual difficulties during the Covid-19 pandemic

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Background Covid-19 triggered individuals with intellectual disability mental health conditions or exacerbated existing ones and brought a sense of anxiety, insecurity, and fear in their caregivers. Therapeutic centers had to adjust their way of work to the new reality imposed by Covid-19.

Methods A descriptive qualitative methodology was applied to explore the challenges in the treatment and care delivery to adults with intellectual disability who visit day care facilities in Varna, Bulgaria. Three health professionals and four social care workers were purposively recruited by snowball sampling via mental health colleagues to pilot test the interview guide. Reflective thematic analysis was used to identify the upcoming emerging themes.

Results/Aim The aim of the study is to share experiences of professionals who have worked with individuals with intellectual disabilities and their families during the Covid-19 pandemic in Bulgaria. Three major themes were identified: obstacles in treatment exacerbated by the pandemic, public and social support to families with members with intellectual disability, parents as partners in the process of service delivery. Sub-themes such as changes to service accessibility and reorganization of the treatment model were reported by participants.

Conclusion Remote technologies have been adopted to address the psychosocial challenges of adults with intellectual disabilities and their parents during the Covid-19 pandemic in Bulgaria; yet their experiences using them have not been perceived as completely helpful. Mobiles phones can be an alternative way to increase independence among people who receive in-home care.

From Science to Practice The study highlights the importance of considering people's with intellectual disabilities needs in pandemic responses as a way to combat existing inequalities.

Keywords Adults, intellectual disabilities, Covid-19, service delivery, challenges

[Topic: Physical Health / Health Inequalities](#)

Understanding inequalities in COVID-19 outcomes following hospital admission for people with ID

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Background People with Intellectual Disability have poorer health outcomes and higher mortality rates than the general population. They also appear to be at a higher risk of COVID-19 infection and greater severity of disease. This study explores the hospital journey of patients with Intellectual Disability compared to the general population after they were admitted to hospital for COVID-19 during the first wave of the pandemic.

Methods A sample of 506 patients with Intellectual Disability were matched on a 1:3 ratio with controls using data from the ISARIC4C ongoing prospective cohort study on patients admitted with Covid-19.

Results/Aims Patients with Intellectual Disability had a 56% increased risk of dying from COVID-19 after they were hospitalised and were dying 1.44 times faster compared to controls. Subjective presenting symptoms such as loss of taste/smell were reported less frequently in patients with ID, whereas altered consciousness and seizures were more common. Patients with ID were 37% less

likely to receive non-invasive respiratory support, 40% less likely to receive intubation and 50% less likely to be admitted to the Intensive Care Unit while in hospital.

Conclusions People with Intellectual Disability may have greater symptom severity at admission. Access to interventions such as ICU and ventilation were less common in people with Intellectual Disability. The possible role of diagnostic overshadowing, discrimination and poor awareness of alternative symptom presentation could be contributing.

From Science to Practice The COVID-19 pandemic appears to have magnified healthcare inequality, with implications for improving care and treatment during a crisis and considerations about how to ensure appropriate monitoring and adjustments are in place to support people with Intellectual Disability during acute illnesses.

Keywords Inequality; Resource Allocation; Discrimination; Healthcare.

Topic: Genetic Syndromes

Impairment of the serotonergic system in temper outbursts in Prader-Willi syndrome PWS and treatment with Selective serotonin reuptake inhibitors (SSRIs)

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Background Challenging behaviours with temper outbursts are common and often combined with physical aggressiveness and self-injury in Prader-Willi syndrome (PWS). They are the most frequent cause for a reduced quality of life in adulthood and represent a serious challenge for the individual and those surrounding the individual in everyday life. Until now, no promising pharmaceutical treatment option has been established.

Methods We investigated the effect of the Selective serotonin reuptake inhibitors (SSRIs) sertraline in 14 individuals with PWS frequently showing severe temper outbursts with aggressiveness and self-injuries. Furthermore, methylation rates of the promoter region of monoamine oxidase A (MAOA) was measured using bisulfite sequencing in 32 individuals with PWS and healthy controls.

Results/Aims The promoter region of MAOA shows a significant hypomethylation in individuals with temper outbursts compared to those not showing outbursts and healthy controls. After 6 months of treatment with sertraline, 13 of 14 patients (92.6%) either no longer displayed temper

outbursts or showed a significant decrease in frequency and severity of temper outbursts.

Conclusions The serotonergic system is impaired in individuals with PWS showing temper outbursts and those outbursts can be treated with SSRIs.

From Science to Practise Temper outbursts in PWS are the most frequent cause for a reduced QoL. We can show, that the impairment of the serotonergic system contributes to the outbursts and can identify a promising psychopharmacological treatment option

Keywords Prader-Willi syndrome, MAOA, temper outbursts, treatment

Topic: Challenging Behaviour

Effects of problem behavior on acceptance and rejection of students with intellectual disabilities in special needs schools

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Keywords social acceptance, rejection, problem behavior

Background Individual social status (i.e., social acceptance and rejection) among peers has important implications for students' social and academic development. Acceptance and rejection of students with intellectual disabilities (ID) in special needs schools has been little studied so far and less is known on factors influencing these students' status. The present study investigated the role of individual problem behavior on the development of social acceptance and rejection in special needs schools. Based on the person-group-similarity- model (Stormshak et al., 1999) the moderating effect of descriptive classroom norms was also examined.

Methods Using questionnaires, school staff at Swiss special needs schools for students with ID provided information on the problem behavior, social status, and background factors of 1125 students with ID (M=11.97 years, SD=3.75; female=31%) at the beginning (T1) and end (T2) of a school year.

Results/Aims More individual problem behavior at the beginning of the school year predicted significantly less individual acceptance and more individual rejection at the end of the school year, controlling for students' initial social status, gender, age, adaptive behavior and classroom descriptive norm at T1. The classroom norm on problem behavior had no moderating effect on the influence of individual problem behavior on social status.

Conclusions Our finding is consistent with results reported for other school contexts where problem behavior has proven to be a risk factor for students'

social inclusion. We will discuss our results in terms of their relevance for the support of students with ID.

From Science to Practise Having identified problem behavior as a predictor of social status, this may help professionals to better understand and intervene in situations where students with ID risk social exclusion among their peers in special needs schools.

Training resistance to peer influence in adolescents with mild-to-borderline intellectual disability

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Keywords mild-to-borderline intellectual disability, training, resistance to peer influence, adolescents, pilot

Background Adolescents with a mild-to-borderline intellectual disability (MBID; $50 < IQ < 85$) often get into trouble due to peers negatively influencing them to make risky decisions. In this presentation, we present our pilot study on a new training aiming to increase resistance to negative peer influence in adolescents with MBID.

Methods The training was adapted from an American protocol (Khemka et al., 2016). We included new aspects such as peer influence videos and role plays with an actor to improve generalization. From April to June 2021, the training will be piloted in a group of 6 adolescents with MBID (13-15 years) at a vocational school. Before and after the training, we will administer self- parent- and teacher-reports about resistance to peer influence, prosocial behavior, peer problems and risk taking, as well as a one-week daily diary on peer influence for adolescents.

Results/Aims We aim to increase resistance to peer influence as well as to decrease risk taking. We explore how training outcomes relate to peer relation indicators such as prosocial behavior and peer problems. In the presentation, we will present the results and our future study plans. Feedback from both scientific and clinical angles is highly appreciated.

Conclusions Based on the pilot results, we adapt our current protocol and instruments.

From Science to Practise As adolescents with MBID often get into trouble due to peer influence, this training has the potential to improve their interactions with peers and to increase social assertiveness.

Is problem behavior development of students with intellectual disability, influenced by their classmates' characteristics?

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Keywords Peer influence, problem behavior, classroom

Background Students with intellectual disabilities (ID) exhibit increased rates of problem behaviors compared to those without ID. Given the evidence of peer influence in typical development, we examined the impact of classmates' characteristics on problem behaviors of students with ID. We expected that the levels of problem behaviors in special needs classrooms will influence individual development of such behaviors.

Methods A longitudinal design with measurements at the beginning and the end of a school year was applied. Staff reported on students' problem behaviors using the Developmental Behavior Checklist. Information on 1125 students with ID (69% boys; age 11.30 years, $SD = 3.75$) attending 16 Swiss special needs schools was collected.

Results/Aims Levels of problem behavior were generally high in the considered special needs settings (i.e., at T1 51.6% and at T2: 49.7% of students had scores above the cutoff indicating clinical relevance). The peer influence hypothesis was not supported regarding an overall score of problem behaviors. However, exploratory analyses suggested that peers tended to influence individual anxiety, problems in relating socially, and communication disturbances (not disruptive, self-absorbed and other types of problem behaviors). More within- classroom heterogeneity of students' anxiety reduced the effect of classmates on anxious behavior. Development of communication skills benefited from attending classrooms heterogeneous in the levels of communication problems.

Conclusions Our results suggest that peer influence on problem behaviors in special needs schools is not universal but may vary between domains and depend on classroom characteristics.

From Science to Practise For some domains of problem behaviors this study suggests that students with ID may benefit from low mean levels and greater heterogeneity of these behaviors among classmates in special needs schools.

Peer relations and problem behaviors in children and adolescents with intellectual disabilities

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Keywords Challenging behaviors, peer relations, peer influence

Background Problem behaviors are relatively frequent in ID and can pose challenges for the concerned children and adolescents and their social environment. A social group of special importance at this age is the peer group. Exhibiting problem behaviors may contribute to a low social status among peers. Also, the behavioral characteristics of the peer group at school may influence the development of individual behavioral problems of students with ID. It would therefore be helpful to have means to help individuals with ID in resisting negative peer influence. We will tackle these issues reporting on findings from three studies.

Methods The studies on social status and peer influence were questionnaire-based and involved longitudinal measurements among 1125 students with ID attending special needs schools. The pilot study evaluating a training of resistance to negative peer influence was conducted in a vocational school.

Results/Aims Our findings show that behavioral problems are frequent at special needs schools for students with ID. In this school setting, exhibiting problem behaviors is associated with less social acceptance and more rejection among peers over time. Some types of behavioral problems are found to be influenced by the levels of these behaviors among the classmates. First insights on the effects of a peer intervention will show how promising this approach may be to reduce negative peer influence.

Conclusions Results presented suggest that research focusing on the peer context can contribute to a better understanding of challenging behaviors and development of individuals with ID.

From Science to Practise We will discuss our results in terms of their relevance for the practical support of children and adolescents with ID in their surrounding peer context

Network for competence development in working with people with CB and intensive assistance needs

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Keywords Inclusion, networking, challenging behaviour

Background The Bodelschwingh Foundations started 20 years ago to decentralize integration support from the Bethel district.

Living and working facilities for people with disabilities were established in various social areas in North Rhine-Westphalia. The importance to develop tailored social support offers for people with CB and intensive assistance needs became obvious.

Methods Based on first experiences for this group of people, it became clear that the competencies needed to be made available to continuously develop the quality of the support services.

The approach of installing a cross-hierarchical and cross-departmental network was developed, planned, and launched in 2014. The project to install a competence network was financed and scientifically supported.

The goals were

- identify and bundle resources,
- develop common standards,
- offer solution-oriented advice and support
- examine, double-check the need for highly structured support, alternatives
- promote discussion about ethical issues and innovation,
- develop infrastructural resources,
- communicate, collaborate with partners.

In addition another committee was established to provide considerable influence on the discussions and the development of standards. Clients meet regularly to work on important topics. The results are directly incorporated into the network and significantly influence the work.

Results The scientific monitoring and the subsequent evaluation showed that the network was able to achieve important successes for the work with people with challenging behavior and had a high level of effectiveness. The project therefore became part of the organization, is still active and supports the facilities in this complex field of work.

Conclusions The focus of the network reacts to the request situations, socio-political requirements, law amendment, etc. The network is transforming, as requests from other organizations keep coming up. To maintain the high standard of the services the network is now to be expanded all over Germany.

[Topic: Empowerment and Independence](#)

The topic of health in the life stories of people with intellectual disabilities

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Keywords Health literacy, life stories, self-determination, decision-making

Background People with intellectual disabilities experience higher levels of ill-health at a young age. They are at an increased risk of chronic diseases,

mental illnesses, obesity and cardiovascular disease. Therefore, they often have to deal with health-related issues in their everyday lives and overcome corresponding challenges. However, due to limited cognitive and communicative abilities, people with intellectual disabilities are often assumed to feature low health literacy and thus low skills and resources in accessing and in dealing with health-related information. As a result, caregivers and professionals in the institutional setting grant them only little scope for decision-making and action with regard to their own health. People with intellectual disabilities thus experience an increased dependence on others in a subjectively significant area of life throughout all phases of life.

Methods Biographical narrative interviews are conducted with people with intellectual disabilities living in residential facilities.

Results/Aims Since health-related decisions and actions entail considerable consequences for individuals, the project aims to elaborate the experiences of the people interviewed and their retrospective assessment of the (health-related) decision-making processes as well as the scope for action experienced throughout their lives.

Conclusions The interviews provide a first insight into how people with intellectual disabilities experience their scope for action and decision-making and to what extent health-related challenges influence their lives.

From Science to Practise Focusing on life stories allows people to look (back) on and reevaluate their own - sometimes challenging - experiences. The approach can promote well-being and act as an empowerment process at the same time. In addition, examining life stories can be an initial point for developing interventions e.g. in respect to educational opportunities.

School closures affecting pupils with intellectual disabilities during the pandemic: Situation and opportunities from the teachers' and parents' perspective

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Keywords Covid-19, digitisation, intellectual disability, schools, education

Background: The closing of schools in Germany caused by the coronavirus-pandemic in the spring of 2020 affected schools more or less unprepared. In winter 2020/21, schools were closed once more and different forms of remote teaching took place. We have accompanied both phases under the perspective

of examining the educational reality of pupils with intellectual disabilities in Bavaria

Methods In May 2020, 391 special education teachers from 89 private schools for pupils with intellectual disabilities took part in an online survey. Additional questions with an open format were analysed via content analysis. In spring 2021, we interviewed 12 parents about their situation at home during distance learning via interviews, focussing on their problems and benefits in this situation.

Results Teachers see gains in communication with parents and in the area of digitisation. Restrictions on social contact with peers is often seen as problematic for pupils with intellectual disabilities. Pupils' lack of communication with their teachers, which is held representatively by their parents, marks another negative effect.

Conclusions Besides negative aspects like lack of direct communication between teachers and pupils also positive aspects can be seen in the impact of the lock down periods concerning pupils with ID.

From science to practise Results show the vulnerability of pupils with ID when there is a lack of social response and structure of the day. They may also lead to new forms of digital communication in these schools

Topic: Models of Care and Support

Systemical impact of socio-emotional diagnostics

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Key words sozioemotional development, impact of assessment intraindividual and systemical

Background The conceptualization of emotional development enables essential new perspectives: - on a persons potential, -on the level of interaction between that person and her or his reference systems, and also - on the current emotional needs of people with intellectual development disorders (ID).

Both in childhood and adulthood knowledge of the emotional development stage leads to more understanding and enriched relationships that also support attachment. Certain mannerism and whimsical behaviours can be better classified and developmentally appropriate educational interventions can be used.

The professionals conducting the assessment has a responsibility to communicate conclusions to parents and the caregivers in an understandable

and plausible way that can result in better support both in conflicts as in everyday life.

Certain domains of the SED-S prove to be more significant in terms of systemic input and can lead to an improved perspective capacity of the system in the sense of milieu enrichment.

Methods Systemic diagnostics and crisis management

Goals A significant relief for clients and caregivers, especially as protection against overstrain

Conclusion To be understood and to be cared for in emotional needs corresponds to an evolutionary human need which also provides the basis for a sense of security. This in turn opens up extended possibilities for learning and development

Von Science bis Practise In relation to psychiatric diagnostics, this approach results in depathologisation, which can lead to a reduction in psychopharmacological therapies

[Topic: Sexuality/Partnership](#)

Gender Incongruence and intellectual disability - What services are provided for this population?

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Keywords Gender Dysphoria, Intellectual Disability, Medical Audit

Background There remains a paucity of studies regarding Gender Incongruence in people with intellectual disability in medical literature. Consequently, an Audit has been conducted across intellectual disability and intellectual disability Forensic services in the United Kingdom (UK) to check the quality of mental health care provided to this population.

Methods All service users reporting gender variance allocated to intellectual disability and Forensic intellectual disability services within Hertfordshire, Essex, Buckinghamshire, and Norfolk (UK) were included. Respective electronic records were reviewed; data were collected and analyzed descriptively.

Results/Aims Records from nine transgender people were analyzed during the initial phase of this audit. Seven service users presented at least one comorbid mental disorder other than issues related to intellectual disability; eight required psychological interventions and five were on regular psychotropics. Although five service users displayed marked incongruence

between individual's experienced gender and the assigned at birth, only two of them had were seen by specialized services. One received hormonal treatment and no surgical interventions were reported.

Conclusions Preliminary results showed a high prevalence of mental comorbidities in the studied population, as reported in epidemiological researches. Less than one third of these people was in contact with gender services, despite of presenting gender incongruence and associated distress. Surgical and hormonal treatments have showed good outcomes in transgender people; nevertheless only one service user from this sample had hormonal intervention. These results may suggest that people with intellectual disability may not have their healthcare needs fully addressed, which could be related to a poor access to specialized services.

From Science to Practise Our results may be helpful to increase the awareness of the clinicians regarding sexuality and gender incongruence among people with intellectual disability.

Topic: Child and Adolescent

What we need to know about callous-unemotional traits and youths functioning?

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Keywords Callous Unemotional Traits, behavioural disorders, mental health; AAIDD model, youths functioning

Background Children and adolescents with conduct disorders (CD) are at increased risk of developing persistent antisocial behaviour in adulthood. Not all follow a negative trajectory, and research explains this heterogeneity by the severity of callous-non-emotional (CU) traits. The study answers a key research question: how do EC traits affect child and adolescent functioning?

Methods A systematic literature review conducted through different databases (PubMed, Scopus and Web of Science) have analysed 52 studies published from 2015 to 2020. In order to analyse the effects of high CU traits on youths functioning, results were articulated around the five dimensions of the AAIDD model.

Results/Aims Out of the 52 studies, 47 analyzed links between CU traits and neurobiological or mental health, 20 family and school contexts, 8 focused on social adjustment, 10 on social interactions and 19 measured links with the cognitive functioning, especially executive functions. Outcomes show that CU traits are not specific to children with conduct disorders but may also be

observed in children and adolescents with other disorders as ASDs or ADHD. This supports other authors' conclusion that early disruptive behaviours could have a neurodevelopmental basis.

Conclusions Results indicate a need to investigate CU traits also with IDD children and adolescents. They also argue for early interventions in both physical health (e.g. nutrient supplementation, environmental enrichment) and family and school care (e.g. positive reinforcement of prosocial behaviors, emotion recognition, parental interventions).

From Science to Practise Assessing the presence of UC traits in early childhood is necessary to prevent the emergence of comorbid disorders by targeting multimodal interventions to positively influence the life trajectories of these young people

[Topic: Physical Health / Health Inequalities](#)

How do multimorbidity and lifestyle factors impact the perceived health of adults with intellectual disabilities?

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Keywords Lifestyle, perceived health, physical health

Background Adults with intellectual disability (ID) have poorer physical and perceived health than the general population. The aim of this study was to investigate factors associated with perceived health, and lifestyle factors and multimorbidity as predictors for perceived health.

Methods A community based cross-sectional survey with use of the POMONA-15 health indicators. Uni- and multivariate logistic regression analyses with poor versus good health as the dependent variable were applied.

Results/Aims The mean age of 214 adults was 36.1 (*SD* 13.8) and 27% reported perceiving their health as poor. Significant associations between poor health

ratings and female gender, lower motor function, number of physical health conditions, and levels of physical activity was found. Female gender (OR 2.4, $p < .05$), level of ID (OR .65, $p < .05$), numbers of physical health conditions (OR 1.6, $p < .001$), and lower motor function (OR 1.5 $p < .05$) were significant explanatory variables for poor perceived health.

Conclusions Women with reduced motor function and more physical health conditions are at increased risk of lower perceived health and should be given attention in health promoting interventions.

From Science to Practise Improving health services through more knowledge of individuals' health challenges may lead to better health and better quality of life.

Topic: [Autism Spectrum Disorder and Related Developmental Disorders](#)

Verbal Behavior for school-aged children with Autism Spectrum Disorder: what does the literature say ?

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Keywords Autism, verbal operant, school-intervention, language disorders

Background Autism spectrum disorders (ASDs) is a lifelong condition characterized by alterations of communication, social relationships and stereotypical behaviours. Approximately 25% to 35% of ASDs children have no or little functional verbal communication. Numerous interventions have been developed to teach verbal communication among them, Verbal behaviour model based on applied behavioural intervention. Despite the contributions of the past reviews on this model, none focused on the effectiveness of teaching verbal operants to school-aged children. The purpose of this study is to review the literature researching ABA- VB interventions and school-aged children (6-18 years old) with ASD.

Methods A systematic literature review analyzed 37 studies published from 2010 to 2019 which included outcomes of 84 ASDs students aged 7 to 18 years. The data were extracted in order to identify trends regarding three categories: 1) Characteristics of studies, 2) Characteristics of intervention and 3) Indications about efficacy of intervention.

Results/Aims Four main findings emerged from the results. 1. The lack of implementation of this model in Europe. 2. An improvement in ASD students' language skills on each verbal operant taught. 3. The possibility to implement this method in classroom. 4. Great heterogeneity in the data reporting between studies.

Conclusions Results underline the need for a systematized and objective process to establish the effectiveness of the interventions in this field. Recommendations for future research are suggested in regard with the great heterogeneity in the data reporting between studies.

From Science to Practise Recommendations for future research are suggested in regard with the great heterogeneity in the data reporting between studies. Teaching communication based on verbal operants seems to offer promising avenues for language development for ASDs students with or without intellectual disabilities.

Topic: Genetic Syndromes

Impairment of the serotonergic system in temper outbursts in Prader–Willi syndrome) and treatment with elective serotonin reuptake inhibitors

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Keywords Prader-Willi syndrome, MAOA, temper outbursts, treatment

Background Challenging behaviours with temper outbursts are common and often combined with physical aggressiveness and self-injury in Prader–Willi syndrome (PWS). They are the most frequent cause for a reduced quality of life in adulthood and represent a serious challenge for the individual and those surrounding the individual in everyday life. Until now, no promising pharmaceutical treatment option has been established.

Methods We investigated the effect of the selective serotonin reuptake inhibitors (SSRI) sertraline in 14 individuals with PWS frequently showing severe temper outbursts with aggressiveness and self-injuries. Furthermore, methylation rates of the promoter region of monoamino oxidase A (MAOA) was measured using bisulfite sequencing in 32 individuals with PWS and healthy controls.

Results/Aims The promoter region of MAOA shows a significant hypomethylation in individuals with temper outbursts compared to those not showing outbursts and healthy controls. After 6 months of treatment with sertraline, 13 of 14 patients (92.6%) either no longer displayed temper outbursts or showed a significant decrease in frequency and severity of temper outbursts.

Conclusions The serotonergic system is impaired in individuals with PWS showing temper outbursts and those outbursts can be treated with SSRIs.

From Science to Practise Temper outbursts in PWS are the most frequent cause for a reduced QoL. We can show, that the impairment of the serotonergic

system contributes to the outbursts and can identify a promising psychopharmacological treatment option

Topic: Child and Adolescent

Fetal Alcohol Spectrum Disorder (FASD) - Enabling Participation for Children and Adolescents

Jörg Liesegang |

Ev. Krankenhaus Königin Elisabeth Herzberge

Background The Fetal Alcohol Spectrum Disorder is being diagnosed increasingly. However, after the diagnosis, there is a great need for the professional management of the development of the child or adolescent. The caretakers are often left alone to face the difficulties within the family or the school. Care-takers and the affected children experience the behavioral impacts of the impaired brain-functions every day. The transfer of these experiences and knowledge to the systems of the nursery school or schools proves to be very difficult. Many helpers have difficulties in excepting impaired brain-function as a possible cause for the behavioral problems.

Methods Introduced is the work of the psychiatric outpatient clinic for children and adolescents at the KEH Hospital in Berlin. From the start of the diagnostic process, the focus lies in participating the biological mother wherever possible to ensure a constructive acceptance of the difficult diagnosis. In the further process, it is ensured that the affected child recognizes his/her own possible impaired brain-functions and opens up to means of adaption and positive self-perception. Another focus is the psychoeducational work with the care-takers and professional helpers.

Results Presented is a clinical on-going process. No current evaluation or long-term results can be presented. We do however have a enormous positive feedback for our approach from the care-takers and associated professionals in school and youth-welfare services.

Aims The aim of this type of psychoeducational work with the affected child and the care-takers is enabling participation.

Conclusions Successful participation of a child with FASD is the key to a healthy social-emotional development

From Science to Practice Using the vocabulary of the International Classification of Functioning, Disability and Health (ICF), we have established a non-validated clinical interview and a hypothesis generating model for guiding this process.

Drop the term ‚challenging behavior‘! – The trivialization of emotional suffering

Klaus Hennis

No institution

Keywords challenging behavior, overshadowing, ethics of support and care

Background One result of years of clinical and counseling work is that the term "challenging behavior" for severe behavioral problems of persons with IDD obscures the view of the underlying mental suffering („overshadowing“).

Methods Clinical and counseling experiences; nonsystematic literature research

Results/Aims Since the beginning of the inflationary development of the term “challenging behavior” in the 1990s, Eric Emerson has called for “more sophisticated 'integrated' theoretical models” to break up the narrowness of traditional medical concepts. Little attention was paid to this demand. With a similar intention, but as a supposedly “better alternative” to the individualizing views of psychology and psychiatry, pedagogy has claimed the term for itself. The associated hopes have not been fulfilled. The term symbolizes the consistently deficient situation of support and care and refers to a lack of concepts in the understanding the forms of emotional suffering of persons with IDD. The "Entwicklungsorientierung" established by Anton Došen is only slowly spreading. In recent years, however, Sappok & Zepperitz have provided further clinical and educational reasons (including the SEED questionnaire). Došen’s actually “sophisticated” concept of “integrative diagnosis”, in which all current approaches could have their place, was not taken seriously. In the mainstream of support, diagnosis and treatment of persons with IDD, the attitude of "overshadowing", a deficient Entwicklungsorientierung and ultimately the rejection of psychiatric-psychotherapeutic concepts (apart from the excessive use of psychotropic drugs) still dominate.

Conclusions A critical re-conceptualisation of the meaningless term "challenging behavior" (or its deletion) could contribute to the development of more appropriate basic conditions, so that - as a matter of course - all knowledge of the human sciences of education, psychology and psychiatry can be used and made available to those affected.

From Science to Practise See Conclusions

[Topic: Ageing/Lifespan](#)

Adverse experiences, stress and resilience in the lives of elderly people with intellectual disability

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Keywords elderly, intellectual disability, adverse experience, resilience, quality of life

Background During their increasingly long lives, people with intellectual disability are reported to frequently experience negative life events that have an impact on their quality of life (QoL), while other factors protect them against stress and trauma.

Methods We interviewed three women and six men with mild ID, all between the ages of 61 – 88 years old, in four 90-minutes focus group sessions on nine domains of QoL. We thematically analysed the data on adverse life events and excessive stress-averting factors.

Results/Aims Our participants encountered many negative, stressful events, which still weigh upon them: e.g. being confronted with one's intellectual disability, physical problems, difficult schooling and work histories, not being accepted, respected or given control, being (financially) abused, losing important people or activities, war experiences had left them sad, angry, anxious or feeling helpless. Without annulling these effects, feelings of belonging, security, control and activity, well-tailored support, being informed and hopeful, having a positive personality, positive experiences and the chance to act upon one's spiritual needs provided protection.

Conclusions Elderly people with mild intellectual disability do reflect upon their long lives and are capable of enjoying and sharing these experiences. They are at high risk of experiencing many 'large and small' adverse life events, of which some specifically relate to the intellectual disability. Nevertheless, our participants expressed contentment with their lives, thanks to several factors protecting them from toxic stress.

From Science to Practise Practitioners do well to keep track of clients' negative life events and provide opportunities for life story work or therapy. Accepting protest as an active coping strategy, maximizing self-control within secure boundaries through wise, well-tailored support strategies are protective.

Dementia in intellectual disability: a training course for daily caregivers

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Keywords Intellectual disability, dementia, expertise, training, formal caregivers

Background The prevalence of dementia, being an age-related disease, parallels the increase in life expectancy of people with intellectual disability (ID). The

Centre of Expertise on Dementia in Flanders (ECDV) developed a training package on dementia in people with ID, to tackle the education needs of their (professional) caregivers.

Methods We set out a modular frame of (sub)themes. Author 1 compiled research and practice based expertise from ID and regular elderly (dementia) care. A core group, both from practice and research, supervised the process. Extra information was sought from several experts.

Results/Aims The first part of the training package educates in cognitive and adaptive abilities, in ID (for elderly care), in dementia in general and in ID. Part two focuses on quality methods of person-centred care such as Validation or Gentle Teaching, on (adaptations in) living and activities, on physical care / ADL and on difficult-to-manage behaviours. Part three informs on aspects of law, where to find help, and staff and organizational issues. Part four provides evidence based reference frameworks for quality of life and quality of care. A workbook is provided within the framework of devising an action plan for client and/or organization. A train-the-trainer will roll out in the spring 2021.

Conclusions The training package aims to educate caregivers who daily support people with ID and dementia and their supervisors, both in ID and elderly care. The first reactions to two online try-outs (+/-50 participants) were positive.

From Science to Practise The training package combines scientific research results with experiential knowledge and hands-on information, bridges gaps between ID and elderly care and families, and links to the governmental Flemish Dementia Plan.

Topic: Communication

Assessment of social communication skills in adults with intellectual disability and deafness

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Keywords Social Communication, Intellectual Disability, Deafness, Caregiver Questionnaire

Background Social communication (SC) includes the use and interpretation of verbal and nonverbal messages within a social context and thus more than the knowledge of language. SC skills are essential for connecting and engaging with others and often associated with emotional and behavior problems. So far, there is a lack of feasible instruments to assess SC skills in individuals with intellectual disability.

Methods A questionnaire on SC (QSC-ID) with a total of only 20 items was developed with the intention to be independent of communication mode (signed or spoken). The QSC-ID was completed for participants of three therapeutic living communities for people with ID and deafness in Austria by their respective key persons in the living and working facilities (n =56).

Results/Aims First results demonstrate high construct validity. Correlations with language and social skills as well as with Autism symptom severity were high, moderate for adaptive skills and low for nonverbal intelligence or motor skills. Interrater reliability was found to be good or at least acceptable for all items. Total raw scores were well distributed over the whole range. Care giver feedback and completeness of data suggest high feasibility of the questionnaire.

Conclusions Findings suggest the potential of the QSC-ID as an easy-to-use instrument to assess SC skills in individuals with intellectual disability and deafness. Further validation in populations with typical hearing is required.

From Science to Practise Case studies will be presented to demonstrate the use of the QSC-ID for intervention planning.

Designing a system that supports caregivers of people with severe/profound intellectual disabilities

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Keywords Emotion detection, Physiological signals, Severe/profound intellectual disabilities, Stress detection

Background Since physiological measurements reflect emotional arousal and stress, these measurements can support caregivers in understanding the subtle, non-verbal communication of people with severe/profound intellectual disabilities.

Methods We designed a monitoring system using a spiral model approach consisting of four iterations. Each iteration was validated with parents of children with Prader-Willi syndrome or caregivers of people with severe/profound intellectual disabilities. In the evaluations, three types of data were collected: (1) physiological data, (2) behavioral observations of the dyad's interaction, and (3) feedback from parents/caregivers using interviews/questionnaires. This feedback was the starting point for the next iteration.

Results/Aims Through using this iterative approach, a monitoring system - consisting of a sensor sock, skin resistance sensor, and a mobile application - has been developed to support caregivers in their interaction with their client. Caregivers responded positively to the system and were observed to reflect on the additional information and their client's behavior.

Conclusions Our results suggest that providing additional information has resulted in caregivers reflecting on their behavioral observations of the client. As a result, we expect that caregivers can attune better to the client's communicative behavior, which in turn may lead to a better quality of interaction and a better quality of life for the client.

From Science to Practise Using an iterative approach that involved caregivers throughout the design process has resulted in a monitoring system that is not only suitable for research, but in a system that can actually be used by caregivers in practice.

Evaluating Talking Mats™ with the inpatient intellectual disability forensic population

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Keywords Forensic, Intellectual disability, communication, risk

Background People with an intellectual disability who are in contact with the criminal justice system (CJS) face significantly higher health inequalities than the general CJS population. Difficulties in communication can lead to information about health being missed and conditions being under treated. (Marshall-Tate et al, 2019). Risk assessment and management procedures play a key role in mitigating risks to individual patients. While there is strong support among forensic professionals for including a patient perspective in such procedures, there is limited academic evidence around how this is best achieved (Fish et al, 2012).

Methods A three-phase ethnographic study was conducted to evaluate the viability of using the symbol-based visual communication tool 'Talking Mats' with inpatient intellectual disability forensic services. Initial interviews were conducted with nurses (n=5) and patients with an intellectual disability to discuss perceptions of risk and safety. Nurses and patients then used the Talking Mats 'Keeping safe' symbol set over four months (March-June 2021), with conversations video recorded for analysis. Finally, participants completed an exit interview to provide their reflections on using the tool. Data

analysis was undertaken using a framework underpinned by Douglas's Cultural Theory (Douglas & Calvez, 1990).

Results The aim was to explore how Talking Mats™ is used within an ID forensic service to discuss personal issues of risk and safety.

Conclusions The results will ascertain if the Talking Mats communication tool helps conversations about risk and safety and whether it can work in a forensic setting to improve the care of patients with an intellectual disability

From Science to Practise This study explores ways to enhance therapeutic conversations around risk and safety between intellectual disability nurses and their patients.

Topic: Families/Parenting

Attachment psychoeducation for parents of children with severe disabilities: A micro-intervention

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Background The belief of parents in themselves, operationalized as parenting self-efficacy (PSE), fosters parenting and the mutual interactions with their children. A micro-intervention consisting of watching four psychoeducational videos on parent-child attachment was piloted in parents of children with severe or profound intellectual disabilities (SPID). The effects on their PSE and general perceptions of attachment were explored.

Methods A mixed methods pilot study was conducted, including 16 parents of children with SPID (up to 10 years of age). Over a three-week period, parents received daily diary measures (in M- path) and three questionnaires (in Qualtrics). The entire study was conducted online.

Results No significant pre-post changes were found regarding parents' PSE. Only small shifts were reported in their general perceptions of attachment (such as in the strengths of their beliefs). However, parents stressed the personal meaning the videos had offered them, because it had stimulated their learning and reflection. Some parents indicated that besides the positives the videos had brought them, watching the exemplary interactions in the videos also made them slightly insecure (though this was not apparent on a group level).

Conclusions Although the clinical relevance of the micro-intervention was stressed by all parents, no significant changes were found over the short intervention period regarding parents' PSE. The psychoeducational video series should moreover be provided with care, bearing in mind and offering individualized support to prevent possible undesirable side-effects.

From Science to Practice The psychoeducational video series can be used in (clinical) practice to support parent-child attachment in families with a child with SPID by stimulating parents' learning and reflection on the topic. Support workers should, however, be attentive to provide the necessary support before and after watching the videos.

Effects of the pandemic on the mental health of carers of people with intellectual disabilities: Quantitative and qualitative findings.

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Keywords mental health, coping, social support, carers, Covid-19

Background The measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers. This study aimed to evaluate the impact of the pandemic on the mental health of family carers of children and adults with intellectual disabilities.

Methods Family carers (mainly parents) of children (N=100) and adults (N=107) with ID, and a comparison group of parents of children without disabilities (N=37), completed an online questionnaire. The survey data were collected while strict lockdown conditions were in place and a subsample of 16 parents were interviewed by phone at the end or shortly after lockdown. The interview recordings were subjected to a thematic analysis.

Results/Aims A high proportion of carers of both children and adults with intellectual disabilities had clinical levels of anxiety and depression. Differences from a comparison group of carers of children without disabilities were 2-3 times greater than reported in earlier pre-pandemic studies. Positive correlations were found between objective stress scores and a variety of mental health and coping outcomes. Despite their greater mental health needs, carers of those with intellectual disability received less social support. The qualitative data provided further insight into the burdens experienced and the coping strategies of parents.

Conclusions The results suggest that the pandemic exacerbated carers' mental health problems. The policy implications of these findings will be considered.

From Science to Practise The current findings have implications for future service delivery for families where one member has intellectual disabilities.

Empowering Mothers of Children with Developmental Delays

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Keywords: early intervention, depression, prevention, empowerment

Background: Supporting mothers to feel capable in caring for children with developmental delays (DD) may reduce the risk of depression. Children with DD often have reduced interest in the environment and display difficulties in establishing contact. As part of early intervention, we designed educational and experiential workshops for mothers and children based on Erskine's Contact-in-Relationship.

Methods: We included 16 mothers and 17 children (7-30 months) in 4 cycles of workshops. Each cycle consisted of 10 workshops, once a week, for 90 minutes. BDI-II (Beck Self-Rating Depression Scale) was used to assess depressive symptoms in mothers at the first and last workshop.

Results: At the initial measure 4 mothers had mild depression, 1 moderate, and 1 severe. In the end, only 3 mothers had symptoms of mild depression. The median at the initial measure was 12 and at the end 8. A statistically significant difference was found between the two measures, with a significantly lower result in the last measurement.

Conclusions: Most of the mothers did not show symptoms of depression. The mothers that showed depressive symptoms in the initial measure had a statistically significant decrease of symptoms at the end of workshops.

From science to practice: Workshops created to empower mother-child relationships are an important protective factor for mother's mental health

Parents mental health and effects of COVID-19 on children with disabilities and their families

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Keywords mental health, COVID-19, parents, children with disabilities

Background Mental health is a dynamic state of inner balance that allows an individual to use their abilities in harmony with universal values of society. One of the life stages during which an individual seeks a new mental balance is parenthood. With knowledge of their child having difficulties, parents are faced with stress, fear and uncertainty. Data from current studies implies that the amount of stress and challenges they face often results in poorer mental health status, frequently leading to higher amount of anxiety, social isolation and

dissatisfaction. Also, currently it can be even more pronounced by COVID-19 pandemic.

Methods Research was conducted by qualitative methodology and data was collected through semi-structured interviews with seven parents of children aged from 4-6 years. Six children had the Down sy., while one child had the cerebral palsy diagnosis.

Results/Aims Results show that main sources of satisfaction are in their own family and immediate social environment. Some of the key factors are support for parents, “free” time, stress coping strategies and support services of state system. The COVID-19 had a big effect of everyday life of parents and their families, caused a lot of stress, lack of socialization, and limited access to expert support and medical institutions.

Conclusions The domain of work that includes the focus on parents and their mental health presents the area of work that still needs to be improved.

From Science to Practise Research through parents’ personal perspective points to aspects that can positively or negatively affect their mental health. It also directs us in the way we need to further improve the support and services available, specifically during COVID-19 pandemic.

Parents of children with disability: coping and resilience

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Keywords Parents, family, children with disability, coping, resilience

Background Parents of children with disabilities experience high level of stress, mental health issues, feelings of devaluation and self-blame, fatigue or exhaustion. These negative emotions are due to the need of intensive long-term care of their disabled child, as well as the absence of systematic family support. Nowadays, daily challenges of those families become more and more intensive due to the corona crises.

Methods The aim of our research was to determinate how parents in North Macedonia deal with their everyday challenges, what are their daily routines, expectations and sources of support. We used convenience sample of 220 families of children with disabilities (intellectual and multiple disability). The survey was done in January 2021 through Google Forms, where a link was distributed to the respondents. The Questionnaire contains sixteen questions divided in three sections: accepting child diagnosis, everyday functioning and building family resilience. Result analysis was conducted using frequency, percentage and chi square with level of significance of $p < 0.05$.

Results/Aims according to the results only 23.6% of the responders ask for professional support for preservation of their mental health. Given the difficult economic situation, especially during the corona crises, it was expected that many parents (70% in our sample) face additional financial challenges in providing appropriate treatment for their child.

Conclusions The results of the research confirm the need of the comprehensive treatment of children with disability, which means active involvement of the family, care for all family members and family functioning as a whole.

From Science to Practise This approach will improve the quality of life of the person with disability and his family.

Topic: [Child and Adolescent](#)

Better Health - Better Lives, a 10 year review of the WHO Europe Declaration
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Keywords Children, Family, Europe, Wellbeing, Policy

Background In 2010, the WHO Regional Committee for Europe endorsed the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families: Better Health – Better Lives encouraging Member States to support their health and wellbeing and advocating direct reform to health care systems and the wider social protection environment, including de-institutionalisation. The authors, commissioned by WHO, aims to provide a review and commentary on progress made across the countries of the WHO European Region since that time.

Methods Information was gained through a key informant methodology using existing networks, previous contributors and additional snowballing methodologies, as well as online searches of organisations working in this area, both at a national and local level.

Results/Aims Progress has been mixed across Europe with reported efforts to incorporate the principles of the UNCRPD into policy and legislation, in order to stimulate change, many respondents also informed of no substantive change over the last decade. Key themes, as relevant to the priorities of the Declaration and data collected are described in the paper.

Conclusions Although progress has been made this remains a group continually left behind. Improvements are needed across all areas of life, whether health service provision or family life. Sustainable progress requires participatory approaches; WHO remains a central to guiding required change.

From Science to Practise Explores the relationship between national policy and practise; provides a context for collaborative working across

organisations and professions and in co-production with children and young people and their families

Disclosures 1Nathaniel Scherer 2Roger Banks - project funded by WHO Europe regional office 2Roger Banks - National Clinical Director, NHS England

Topic: Models of Care and Support

Beyond 'spheres of exclusion'. Individualized support for persons with complex needs

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Keywords Challenging Behavior; Inclusion, Society and Community; Models of Care and Support, Profound Intellectual and Multiple Disabilities; Quality of Life and Wellbeing

Background By now, complex support needs of persons with intellectual disabilities are being intensively discussed. This group appears to have a high risk of being referred to and to remain in specialized facilities. Three groups seem to be particularly vulnerable in this context: Persons with an intellectual disability and a) so-called challenging behavior, b) profound or multiple impairments, or c) advanced age.

Methods The outlined presentation is based on sixteen semi-structured interviews with persons with intellectual disabilities and complex support needs and their support workers, that were analyzed referring to theories on quality of life and socio-spatial social work. The sample covers persons living in support arrangements from large-scale facilities to individualized support in small groups or an own flat.

Results Results suggest that specialized facilities act as 'spheres of exclusion' and have a negative impact on resident's quality of life and social spaces. This effect appears to be reduced for persons in small-scaled housing arrangements.

Conclusions Due to the negative effects of 'spheres of exclusion', alternatives in support must be discussed, not only against the backdrop of the UN CRPD.

From Science to Practise Smaller housing arrangements appear to have less negative effects for residents than 'traditional' settings. Against this background, it is important to ask how such arrangements can be implemented in the face of complex needs. International experiences can be taken up but have to be linked to local/regional developmental paths.

Forms of support for patients with comorbid intellectual disabilities and psychiatric disorders in Poland

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Keywords intellectual disability, psychiatric disorders, treatment, rehabilitation, forms of support

Background The aim of this review was to analyze the different forms of care for persons suffering from intellectual disability and mental health problems in Poland.

Methods Analysis of available documents on the policy and organizations of systems of services for this group of patients was performed.

Results In Poland we still observe a shortage of special psychiatric services dedicated for patients with intellectual disabilities. Those with comorbid psychiatric disorders are treated in general psychiatric wards or hospitals or in outpatient settings. The persons staying in the long-term care institutions are usually visited by a consultant psychiatrist every 2-3 months. In the case of more serious challenging behavior or psychotic exacerbation, they are referred to a local general hospital. Some changes in this situation are expected in the course of the implementation of the National Program of the Mental Health Care, which postulates the creation of so called Centers of Mental Health, which would be responsible for the development of community psychiatry services for different groups of psychiatric patients.

Conclusions The main conclusion of this review is that the specialist working with persons suffering from intellectual disabilities in Poland face many challenges regarding the need to improve the system of care for patients with comorbid intellectual disability and psychiatric disorders.

From Science to Practise There is also a need to prepare and publish guidelines for Polish specialists, on proper diagnosing and treatment of persons with intellectual disability, with the focus of their special needs.

Model of interdisciplinary outpatient care

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Keywords Outpatient care, challenging behavior, evaluation, interventions, SED-S

Background A specialized unit was conceived with knowledge from curative education, child psychiatry, trauma therapy and with neuropsychiatric background to meet the need for outpatient care. The team works in special

schools and centers to avoid inpatient treatment as much as possible by supervising and coaching the caregivers and teachers and parents.

A diagnostic phase is assessed in order to locate the focus of the triggering imbalance. Cardinal themes that can affect behavioral regulation are considered such as: developmental status (emotional, cognitive), psychosocial stress, psychiatric disorders, traumas, autism spectrum disorders, genetic disorders, somatics (acute or chronic pain, epilepsy, metabolic or neurophysiological dysfunctions),

Methods A systemic way of working is practiced: -all relevant systems are included- and a multimodal approach (f.e. developmental orientated, trauma release) is used.

Goals The goal of the interventions is to bring in extended possibilities through an outside view and specialized knowledge in order to support a development from maladaptive behavior to socially integrable behavior and self-regulation of the Ch/Ad with ID.

Conclusions The specialized unit supports therapeutic processes and makes pedagogical and medical recommendations. Trauma-relieving therapeutic approaches are offered. The staff of the specialized center are available as coaching partners in the event of new crises.

This has made it possible to stabilize more than 90% of the registered students on site and without inpatient treatment phases.

From Science to Practise Through the application of SED-S and its appropriate pedagogical approaches was it possible to bring about both, improvement in challenging behavior and relief for caregivers

Predictors of Mental Health Crises among People with Intellectual/Developmental Disabilities in the START Program

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Background Individuals with intellectual and developmental disabilities (IDD) disproportionately use emergency psychiatric services, suggesting the individual and their supports are at increased risk for crisis events. To our knowledge, no prospective study has examined, in real time, the epidemiology of mental health crises among individuals with IDD.

Methods Data for this study came from START (Systemic, Treatment, Assessment, Therapeutic, Resources, and Treatment), a national crisis prevention and intervention model for persons with IDD. The sample included 1188 youth and adults (M= 23y; SD = 12y), who received services (M days enrolled = 281; SD = 109) across 13 US states in 2018/2019. The outcome was

urgent crisis contacts to the START program, which is monitored 24/7. Baseline predictors were examined via multivariate negative binomial regression models.

Results/Aims A quarter had at least one crisis contact; 10% had 3 or more contacts. Crisis contacts increased in the first three months of enrollment, followed by a steep drop off; few contacts happened after one year. Almost half of contacts occurred after hours and 30% involved police. Clinical (e.g., ABC scores, lower levels of ID), demographic (e.g., 22-34 years, non-binary gender), and service-related (e.g., psychotropic medications, previous hospitalization, and lack of employment) factors were predictive of crises (all $p < .05$).

Conclusions For those with IDD and significant mental health needs, crisis stabilization resources are needed over time, including nights and weekends. Cross-systems training and collaborations with emergency professionals, and access to gainful employment (for adults) are critical.

From Science to Practice Findings can be used to develop effective crisis prevention and intervention supports for people with IDD.

Topic: [Inclusion, Society and Community](#)

CONF.I.A.N.Ç.A | a moment of stillness, self-reflection and connection

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Keywords Mental health, urban living, awareness, mindfulness, safe space

Background CONF.I.A.N.Ç.A is an experience, when one can dive into an action of contemplation, self-healing and confession. The intention is to address spatially mental & emotional health issues, that are already present in the cities, because of our everyday and lifestyle choices, though currently more evident due to the COVID-19 crisis; to raise awareness over the causes & effects and present the fact that we are part of the problem as much as of the solution. Currently around 4.4 billion people live in cities. On average, city dwellers have access to better infrastructures. What about mental health though? Urban living is associated with increased risk for chronic disorders, anxiety & mood disorders, social fragmentation & disparities. Urban living can be loud & also lonesome. To stop the “noise” & seeking for amity, we often turn online. Is this a solution or we are just making it all worse?

Methods/Aims Is the answer going rural? Well, not necessarily; we do, however, need to rethink how we design our cities. CONF.I.A.N.Ç.A is visualized as a spot for stress release, anxiety moderation and creation of meaningful connections; a point for introspection & healing.

Conclusions Thereby, the public space can be experienced in a different way, as a safe space created to unwind and express oneself. It could be a structure forming a silent garden, a little sanctuary, within the urban context.

From Science to Practise Eventually if CONF.I.A.N.Ç.A is multiplied and a network is created, what is designed as a guided ritual, a point of placidity, could easily be transformed into a tool for mapping a city according to stress or loneliness, giving valuable information to planners, architects, designers for future interventions.

Identifying and linking leverage points to inventions based on 'dynamic personal network stories'

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Background An assessment tool, named 'dynamic personal network story', based on the ecological framework of Simplican et al., (2015), was developed. This tool maps (1) the needs and wishes concerning social relations of a person with a disability, (2) the risk- and protective factors on an individual, interpersonal, organizational, community and socio-political level, and (3) the past, present and future dynamics regarding social relations. With these data, a personal network story is created which yields leverage points for interventions to enhance social relations. An extensive inventory of possible interventions was created by combining literature and a structured inquiry of good practices from ambulatory home-based services, revised by experts.

Methods The identification of leverage points within these stories and the match with specific interventions is evaluated through ten case studies within ambulatory home-based services. Information to create a personal network story in each case is gathered from the person with a disability, his/her network member and his/her support worker. Afterwards, focus groups consisting of professionals from different services will (1) identify the leverage points for intervention within each personal network story and (2) rank the most suitable interventions to enhance social networks in this case.

Results The potential of the assessment tool to identify leverage points for specific interventions is explored and evaluated.

Conclusions Tailored interventions to enhance social networks could be matched to the specific needs and wishes of persons with a disability, taking into account the past, current and future dynamics in their lifespan and influencing variables on different levels.

From Science to Practice This instrument forms an alternative to analyze the social network of a person with a disability. It could be used as a basis to match specific interventions.

Psychology students' education, experiences & attitudes toward people with intellectual disabilities

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Keywords Attitudes, education, knowledge, personal experience

Background When psychotherapists' hold negative attitudes toward people with intellectual disabilities or lack knowledge of intellectual disabilities, this can have an impact on the treatment provision for this patient group. This study aims to investigate the association between the knowledge, personal experiences and attitudes of psychology students towards people with intellectual disabilities.

Methods 94 psychology students, mostly woman (90.4 %) with a mean age of 24.66 years (SD = 4.5), completed a demographic questionnaire, a German Adaption of the Multidimensional Attitudes Scale Towards Persons With Disabilities (G-MAS-P), clinical vignettes of persons with dual diagnoses to assess students' knowledge about intellectual disabilities, a questionnaire to assess students' attitudes toward psychotherapy with people with intellectual disabilities, and additional items to assess students' education and personal experience with people with intellectual disabilities.

Results/Aims Most participants reported having had contact with persons with ID (n = 75). Although 89.3

% of the participants (n = 84) wanted to attend a university course about ID, only twelve participants actually had received some education about ID. For the clinical vignettes involving patients with ID, only seven participants provided accurate diagnoses. Further statistical analyses will be conducted to examine the relationship of education, knowledge, personal experiences and attitudes.

Conclusions Findings are discussed in light of expressed attitudes by psychology students, their previous experiences with people with intellectual disabilities and their education through university. Indications of diagnostic overshadowing are already present in psychology students.

From Science to Practise Understanding and addressing the mediating role of education on indices of diagnostic overshadowing and negative attitudes of psychology students towards people with intellectual disabilities may improve the accessibility of psychotherapy for people with intellectual disabilities.

Topic: Quality of Life and Wellbeing

Compassion focused therapy for people with intellectual disability: a scoping literature review

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1

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Keywords CFT, intellectual disability, compassion, shame, self-criticism, negative comparison, well-being, literature review;

Background People with intellectual disabilities are at higher risk of shame-related distress and experience higher levels of self-criticism. There is a tendency to use downward social comparisons when comparing themselves negatively to others. Compassion Focused Therapy is commonly used to support people with high levels of self-criticism and shame, and strong supporting evidence related to treating people with shame, self-criticism, depression, and anxiety is present.

Methods A scoping review was conducted using the different databases. Descriptive-, review- and experimental studies were included. The search focused on: intellectual disability and visual-and-intellectual disabilities; compassion focused therapy; compassion; shame; self-criticism; and social comparison. English and Dutch articles were included.

Result The literature indicates that Compassion Focused Therapy is adaptable for people with intellectual disabilities. Significant reductions in self-criticism and unfavorable social comparisons were found. CFT can contribute to the well-being of people with intellectual disabilities.

Conclusions Literature shows that CFT is adaptable and seem to be clinically useful for people with intellectual disabilities. However, more research is needed as only limited studies are reported.

From Science to Practise This study underscores the possibilities of the use of Compassion Focused Therapy in practice. It provides an overview on the current literature on CFT with examples of positive change from shame-related distress, such as 'I am worthless' to an accepting way of thinking, such as 'I am a valuable person'. More studies need to be conducted to confirm the positive effect of the intervention.on the current literature on CFT.

Integrative Multidisciplinary Approach to Mental Health of Persons with Intellectual and Developmental Disabilities

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Keywords European co-production, family support, emotional development, empowerment, local community

Background The association L'Arche-Korablja presents a project in partnership with the Center for Rehabilitation Zagreb and a Belgian partner with the aim to empower persons with Intellectual and Developmental Disabilities and their families to be active members of local community and take care of their mental health. In Croatia, 82% of persons with disabilities live in families mostly without appropriate support from a professional team specialized in mental health of persons with Intellectual and Developmental Disabilities

Methods As part of the project, we formed a multidisciplinary team(MDT) of experts (special educators, psychologist and psychiatrist) and supervisors from different organizations, with the aim to provide mental health care for people with Intellectual and Developmental Disabilities from a developmental perspective.

Results/Aims Due to COVID-19, we changed the plan for a study-visit to specialized clinics in Belgium and conducted on-line education and supervision provided by Belgian partners. The MDT prepared 6 cases with recommendations for integrative treatment for families and professionals.

Conclusions In order to meet the needs of people with Intellectual and Developmental Disabilities and improve their quality of life, the MDT is formed. With regular meetings and supervisions, we recognize the rights of people with Intellectual and Developmental Disabilities for adequate mental health care treatment and help them achieve this in practice

From Science to Practise By applying Došen's integrative approach to mental health problems of people with Intellectual and Developmental Disabilities, we support families in adapting environment to the needs of their family member with Intellectual and Developmental Disabilities and empower them to make contribution in local community.

Pain recognition in children and adults with rare genetic syndromes and intellectual disability

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Keywords Pain, neurodevelopmental disorders, genetic disorders, intellectual disability, qualitative study

Background Cornelia de Lange, Rubinstein-Taybi, Pitt-Hopkins and Marshall-Smith syndromes are neurodevelopmental disorders that predispose to painful physical conditions, such as gastro-intestinal problems and skeletal deformities. Due to the associated intellectual disability (ID), timely pain recognition is challenging for parents and professionals. This study maps parents' experiences with recognising pain.

Methods Collaborating with patient support groups we performed a multi-modal qualitative study. Parents shared experiences regarding pain in their child using online theme rooms and a quasi-structured questionnaire. Additionally, structured interviews were held with parents, medical experts and developmental psychologists. Data was analysed using grounded theory for theme rooms and questionnaires and thematic synthesis for interviews.

Results/Aims Data from parental narratives (n=12), questionnaires (n=13) and interviews (n=20) were collated. Recurring thematic outcomes were (1) behavioural changes can be caused by either pain, stress, fatigue, or overstimulation, (2) their child shows unique and idiosyncratic pain behaviours, and (3) parents are unable to specify complaints and convince others (doctors, caregivers) about their concerns.

Conclusions Recognising pain is challenging due to communication impairments and ID, but parents and regular caregivers learn to recognise subtle differences between well-being and moments of pain or stress. Healthcare providers should use the tacit knowledge of parents regarding their child's pain expressions in searching for a possible medical cause for a behavioural change.

From Science to Practise Results from this study will be used to empower parents in recognising pain signals of their child and help them transfer those signals to medical professionals for a collaborative diagnostic work-up. The results are a strong incentive to organise individual pain behaviour observation plans, and illustrative videos to enhance pain recognition in individuals with genetic syndromes and ID.

Predictors of job satisfaction among staff in care settings for individuals with intellectual disability

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Keywords Job satisfaction, quality of work, burnout

Background A growing number of studies could demonstrate that care workers who report higher levels of job satisfaction show higher commitment and provide better services than dissatisfied staff (e.g., Acker, 2004; Hickey, 2011). Therefore the purpose of this study was to analyze aspects of job satisfaction in daily work with people with intellectual disability (ID) and to investigate whether personal burnout is associated with health related and quality of work constructs.

Methods Questionnaire data were collected from 138 direct and 31 non-direct care members in two institutions for individuals with intellectual disability in Luxembourg. Evidence-based indicators for job satisfaction were derived from the “Quality of Work Index Luxembourg” (Steffgen, Kohl, Reese, Happ & Sischka, 2015).

Results/Aims Analysis showed strong correlations between job satisfaction and several quality of work constructs (feedback, cooperation,...) Furthermore findings suggest that there is a substantial association between personal burnout and different health related (mental wellbeing) and quality of work outcomes (job motivation).

Conclusions In terms of getting a holistic view of satisfaction within the institutions, data from individuals with intellectual disability as well as from family members will be collected.

Quality of Life of Parents Caring for Adult Children with Intellectual Disability

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Keywords: family support, respite, WHOQOL-BREF, empowerment

Background: We present the project “Development of the service Respite Care to empower adults with intellectual disabilities and their families” which has started in June 2020 and is approved for two years. We bring the research on the initial quality of life (QoL) of parents living with their children with ID.

Methods: Fifteen parents (50-84 yrs) assessed QoL with the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF) that covers 4 domains: physical and mental health, social relationships and environment, and two separate items assessing general QoL and satisfaction with health.

Results: General QoL was rated acceptable for 7 parents (5 category scale from very bad/dissatisfied to very good/satisfied), good for 4, and bad for 2 parents. Health dissatisfaction expressed 5 parents, 4 were satisfied, 3 parents were neither dissatisfied nor satisfied, and 1 parent was very satisfied with general health. In all domains, parents assessed their QoL within 55-65% of the maximum scale range. The median result for physical health and the environment was 63 and for mental health and social relationship 56.

Conclusions: Considering low results of parental QoL and the non-existent respite care social service, we created the project with activities of support and respite for parents with the goal to improve their impaired QoL.

From science to practice: With project activities including regular home visits of assistants, residence opportunities for children, multidisciplinary mobile team support, and thematic workshops we enable much-needed time for respite and empower parents to broaden their social network.

Topic: [Borderline ID](#)

Deficit or Delay? Executive functions in 8 to 17-year-olds with borderline intellectual functioning

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Keywords Executive Function, Borderline Intellectual Functioning, Working Memory, Attention, Delay

Background Executive functions (EFs) in children and adolescents with mild intellectual disability (MID) or borderline intellectual functioning (BIF) are frequently perceived as 'deficient' compared to typically developing peers. This cross-sectional study diverges from pointing out EF- deficits, but investigates if there may be delayed development of EFs from 8-17 years particularly for youth with BIF.

Methods 409 youths participated (aged 8.02-17.99; stratified per year), with MID, BIF or average intelligence (AIQ). EFs working memory, focused attention, cognitive flexibility, and inhibition were measured with performance tasks in a mobile app.

Results/Aims BIF and MID youth scored similarly on cognitive flexibility from 8-to-12 years old, both lower than AIQ ($F=8.46, p<.001$). From 13 years old on, cognitive flexibility scores of BIF youth were similar to AIQ ($F=20.69, p<.001$).

These delay-patterns for BIF were also found for focused attention; reaching similar levels as AIQ youth during adolescence. Working memory scores of children with MID and BIF were similar from 8-12; both lower than AIQ ($F=6.65, p<.01$). During adolescence working memory scores diverged for all three IQ- groups, who differed significantly from one another ($F=22.58, p<.001$). In-depth analyses on inhibition are forthcoming.

Conclusions This cross-sectional study shows a potential delayed development of EFs: focused attention and cognitive flexibility for youth with BIF from 8-to-17.

From Science to Practise Our study provides a positive perspective for delayed versus deficient abilities of 8-to-17- year-olds with BIF. This impacts the lowering of our expectations about their cognitive abilities and overestimation during childhood, and focuses on supporting development of these cognitive attention abilities more so during adolescence, for example for academic performance.

Topic: Education and Employment

Design and Testing of a Virtual Reality Mentalization Module

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BACKGROUND: By using mentalization-based skills persons with intellectual disabilities' (ID) information processing can be supported, reducing their stress levels. Therefore, it's imperative for professionals to practice mentalization skills. A Virtual Reality Mentalization Module (VR-MM) was developed for learning mentalization-based skills. A pilot study examining the effect and validity of VR-MM was conducted.

AIM: The aims are (1) to widen the scientific knowledge base on the potential for using VR for education and training purposes, (2) to explore the possibilities and challenges for mentalization training to be provided through VR rather than face-to-face, and (3) to examine the effect of the newly-developed VR-training program.

METHODS: The VR-MM module was developed at Vrije Universiteit Amsterdam within a multi-disciplinary team: researchers, IT specialists, a scientist-practitioner and a co-researcher (person with ID). An avatar of a person with ID was created. Students participate in the study within a clinical skills course. They're randomly divided into an experimental group receiving the VR-module and a control group receiving the written information which is typically provided in the course. A multiple-choice test of mentalization skills and a social validity questionnaire are completed by both groups.

CONCLUSIONS: The expectation is that participants in the intervention group will demonstrate higher mentalization knowledge than control group participants.

FROM SCIENCE TO PRACTISE: The innovative VR-MM gives students the opportunity to practice and improve their mentalization skills in coping with challenging behaviour of people with ID. It gives the opportunity to, in a safe environment, experience the consequences of (non-)mentalizing reactions. The aim is to implement VR-MM in a mobile unit so that the VR-MM program could easily be implemented in teaching.

[Topic: Autism Spectrum Disorder and Related Developmental Disorders](#)

Diagnosis of Autism-Spectrum Disorder in Adults with Intellectual Disabilities

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Keywords Autism-Spectrum Disorder (ASD), Diagnosis, AWMF S3-Guideline, Adults, Intellectually Disabled

Background In 2016 part 1 of an evidence based S3-guideline on autism-spectrum disorder in children, adolescents and adults dealing with "Diagnosis" has been published. Among the different representatives of scientific, professional and lay-organizations the author took part in the development of this guideline as an adult-psychiatrist.

Methods In a participative effort working groups of representatives of 15 German scientific, professional and lay-organizations reviewed the international scientific literature on ASD up to 2013. After evaluating their quality and level of evidence, recommendations according to previously formulated key questions were finally consented, guided by a representative of the "Arbeitsgemeinschaft der Wissenschaftlichen Fachgesellschaften e.V./AWMF" and published as an evidence-based guideline on the website of the AWMF

.Results/Aims If a diagnosis of ASD is suspected in intellectually disabled adults, the questionnaires "Fragebogen zur Sozialen Kompetenz/FSK" and "Skala zur Erfassung von Autismus-Spektrum-Störungen bei Minderbegabten/SEAS-M" may be used as screening instruments.

Conclusions For a valid diagnosis, because of lack of scientific evidence, no further instruments can be recommended. If ASD is suspected, the diagnostic process should be continued by a specialized centre as defined in the guideline.

From Science to Practise The AWMF S3-guideline will help social networks, institutions and professionals to early recognize, screen and diagnose ASD in

intellectually disabled in order to enable adequate support and therapy for them.

Psychometric properties of the Psychopathology in Autism Checklist (PAC) in adolescences and adults

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Background Psychiatric disorders in individuals with co-occurring autism spectrum disorders (ASD) and intellectual disability (ID) are common, but diagnostics presents many challenges. The Psychopathology in Autism checklist (PAC) is among the very few instruments specifically developed for this group of individuals.

Methods In a clinical sample of adolescents and adults with ASD and ID referred for psychiatric assessment, psychometric properties of the PAC (i.e. criterion validity, specificity, sensitivity and predictive values) were explored by comparing scores with assessments on the Aberrant Behavior Checklist (ABC) and examining how well assessment by the PAC at referral predicts final clinical diagnoses.

Results/Aims Participants (n= 123) were assessed at referral, after one year and after two years. Correlations between the PAC and the ABC at each time point were all significant. Sensitivity varied between .79 - .38 and specificity between .85 to .51. Sensitivity for any psychiatric disorder was .72 and specificity .47. Positive predictive values (PPV), was high (.77) for “any psychiatric disorder” but lower for specific conditions.

Conclusions The significant correlations with the ABC add to previous findings of clinical validity of the PAC. Sensitivity and specificity for specific diagnoses were variable, although positive predictive value for “any diagnosis” was relatively high.

From Science to Practise The study confirms the potential value of the PAC as a screening checklist but highlights the need for clinical diagnosis to be based on a multimodal, multidisciplinary assessment.

Topic: Ethics and Human Rights

Disgust – a long-acting mechanism for social exclusion of people with intellectual disabilities

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Keywords disgust, prejudices, attitudes, manipulation, history

Background Until today people with intellectual disabilities are confronted with negative attitudes and prejudices as barriers hampering their inclusion. In the past the physical extinction of people with disabilities was the most extreme form of exclusion, e. g. the killing of people with mental illnesses or disabilities during so-called “euthanasia” in Nazi Germany. Today we may recognize more subtle forms of fatal exclusions such as prenatal testing.

In the past societies were manipulated often in order to agree with exclusion of people with disabilities. Provoking disgust is one of the most efficient and long-acting methods for manipulating the attitudes of public and even of professionals. Looking away from people with intellectual disabilities in disgust was intended.

Methods The analysis of the phenomenon of pointedly evoked disgust goes back to the history. It takes up the conception of “changelings” (in German: “Wechselbalg”) known since medieval times all around Europe, selected descriptions and illustrations in medical textbooks regarding people with disabilities in the 19th and 20th century, the book “The Kallikak family” (Goddard 1912) in the USA, propaganda films and schoolbooks during the Nazi time in Germany etc.

Results/Aims The investigation of historic examples of pointedly evoked disgust reveals deep reaching mental roots of prejudice and negative attitudes against people with disabilities.

Conclusions It is to assume that some effects of such manipulations by evoked disgust are still alive. They may be operative in an unconscious way.

From Science to Practise It needs our awareness to identify disgust and other emotions as mental barriers in the public and our engagement to overcome them.

Leo Kanner - a strong opponent of euthanasia in “feebleminded” children

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Keywords Leo Kanner, euthanasia, history

Background Leo Kanner (1894-1981) is well-known as one the most outstanding pioneers in the field of autism. In contrast his engagement against euthanasia

for children is little-known. The historic background of his engagement was the sympathy of some American psychiatrists for the radical measures against people with mental disorders following the Nazi-German example in the 1940ies. Foster Kennedy (1884-1951) was one of the most prominent representatives in this context. He published in the American Journal of Psychiatry his position in favor of murder of “feebleminded” children. Kanner responded with six arguments and rejected the idea of euthanasia. The editors of the journal took Kennedy’s part in their comment of the debate.

Methods The presentation analyzes the debate published in the American Journal of Psychiatry in 1942 within its historic context, and evaluates the arguments of Leo Kanner in detail.

Results/Aims Leo Kanner responded to Kennedy with fundamental and pragmatic arguments. He alleged six reasons against the proponents of euthanasia. He rejected the idea of euthanasia fundamentally .

Conclusions The clear position of Kanner against euthanasia was very important for the debate in the USA in the 1940ies. It seems to be he was able to strengthen the resistance against the continuation of the euthanasia debate.

From Science to Practise The moral conduct and some of the arguments of Kanner are relevant up to today.

Issues of research ethics in the context of so-called mental and/or multiple disabilities

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Keywords ethics, research ethics, intellectual disability, human dignity, participation

Background In order to act in a human rights-based and subject-oriented manner in research contexts, a profound engagement with the discourses related to research ethics is essential. In the presentation we want to introduce the research ethics document (<https://www.difgb.de/forschungsethik/502-forschungsethik>) issued by DIFGB (Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für Menschen mit geistiger Behinderung). It is intended as an orientation framework for research and attempts to identify and make visible some ethical problems and challenges. With special reference to the group of people with so-called intellectual and/or multiple disabilities, questions for critical reflection on one's own research actions (from planning, to concrete implementation,

to dissemination of results) are developed and made applicable to the research process.

Methods In developing this paper, fundamental ethical and human rights principles were taken into account, as were principles of applied ethics and aspects of practical research.

Results/Aims With this paper we want to make a contribution to sensitize for special issues of research ethics in the context of so-called intellectual disabilities, and promote participatory and inclusive research designs.

Conclusions In future, questions of research ethics must be given greater consideration within research practice and be regarded as an indispensable framework condition and prerequisite for research in general.

From Science to Practise With our reflection paper on research ethics, we want to make a contribution to designing research more closely than before to the concerns and needs of people with so-called intellectual disabilities, despite all the difficulties involved.

Topic: [Health Literacy](#), [Health Promotion](#), [Health Education](#)

Health literacy in people with intellectual disabilities: Strengths and weaknesses

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Keywords health literacy, intellectual disability, qualitative research, health promotion

Background Compared to the general population, people with intellectual disabilities represent a disadvantaged group regarding health opportunities. Health literacy has become increasingly important for promoting health-related autonomy and self-determination. Efforts are being made to increase health literacy of people with intellectual disabilities through interventions. Although, self-perceived strengths and weaknesses of people with intellectual disabilities are essential for intervention less is known about those.

Methods 14 guided qualitative interviews with people with intellectual disabilities were conducted. Participants had mild to moderate intellectual disabilities and lived in two different institutions. Transcripts were analyzed via qualitative content analysis.

Results/Aims Strengths: Ten categories were identified. Generally, in addition to a high level of respondents' reflectiveness, the participants are active when it comes to researching health information or implementing health-promoting behaviors in practice. **Weaknesses:** Four categories were synthesized. Overall, they indicate challenges in critically assessing health-

related information and pronounced personal dependencies. Altogether: Strengthen Health Literacy was perceived as important for well-being and mental health.

Conclusions For the development of effective interventions to promote health literacy and health-related autonomy, multiple strengths of people with intellectual disabilities must be considered. In particular, their strong self-awareness skills and intrinsic interest in health topics serve as an excellent starting point. In addition, interventions should strengthen people with intellectual disabilities in critically reflecting on sources of health-related information.

From Science to Practise Based on the findings, videos will be developed to promote people with intellectual disabilities 's health literacy and motivate them to engage in health-promoting behavior. To encounter weaknesses in health behavior produced videos will promote health literacy and autonomous health-promoting behavior tie in with strengths.

Smoking cessation in people with mild intellectual disabilities (MID): a motivational approach

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Keywords Addiction, smoking, mild intellectual disabilities, direct support staff, physical health.

Background Smoking rates in people with mild intellectual disabilities (MID) are high, estimates of 74 percent have been found. However, little evidence based interventions to promote smoking cessation among people with MID have been found. Aim of the current study was to develop and pilot test an intervention to increase motivation to stop smoking in people with MID.

Methods Alongside a staff training in Motivational Interviewing (MI), in cooperation with a certified MI-trainer, staff and people with MID, a motivational intervention was developed. The intervention was pilot tested with eleven clients with MID. Both qualitative and quantitative information regarding smoking rates and motivation to stop smoking was collected.

Results/Aims Questionnaire results showed that clients increased in their perceived importance to stop smoking. Furthermore, three clients stopped smoking and three clients decreased smoking. Interview results coloured the stories behind the quantitative results, highlighting clients perceived barriers to stop smoking, such as negative life events and continuous high stress levels.

Conclusions The current study shows that effective interventions for smoking cessation in people with MID must consist of multiple elements, following the

client path and life. From stress reduction to motivation, to actual smoking behavior ending with a flexible follow up.

From Science to Practise In the current study, professionals and clients co-created a motivational intervention, to increase motivation to stop smoking. With this intervention, inclusion of people with MID was promoted by creating more equal possibilities to quit smoking.

Topic: Mental Disorders

Identification of post-traumatic stress disorder in autistic adults with intellectual disabilities

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Keywords PTSD, post-traumatic stress disorder, autism, intellectual disability, assessment

Background Autistic individuals with co-occurring intellectual disabilities are more frequently exposed to potentially traumatic experiences, and may be more vulnerable to developing post-traumatic stress disorder (PTSD). However, identification of PTSD in this population remains challenging, particularly in individuals with limited verbal language skills.

Methods Mixed-method study including: systematic review of symptom manifestations, retrospective qualitative exploration of sexual abuse non-detection, qualitative exploration of 18 experienced clinicians' experiences of identifying PTSD in this population, quantitative exploration of associations between potentially traumatic experiences and behavioural symptoms in a clinical sample (n=171).

Results/Aims There is a risk of overlooking or misinterpreting symptoms of PTSD in this population. Re-experiencing may be challenging to recognize, while avoidance may manifest in a wider range of ways. Altered arousal/reactivity and negative changes in mood/cognition are likely to be the most easily observable signs of PTSD, but may be misinterpreted as anxiety/depression, "challenging" behaviours, or misattributed to autism.

Conclusions Multimodal assessments seem necessary, including systematic assessment of possible PTSD symptoms and trauma histories. Clinicians need to be aware of the specific life circumstances of these individuals, including how these may involve risk of traumatic experiences which are unusual in the general population. From Science to Practise Due to the

increased exposure, it is recommended that psychiatric assessments in this population routinely include trauma histories and assessment of possible PTSD symptoms, even in the absence of known trauma. This includes awareness of how differences in understanding and perception may also affect what is perceived as traumatic.

Identifying the links between common mental health conditions and dementia onset in a Down syndrome cohort

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Keywords Down Syndrome, Alzheimer's disease, mental health, diagnosis, cognitive decline.

Background Down syndrome (DS) is the most common genetic cause of intellectual disability and Alzheimer's Disease (AD). In the general population, common mental health disorders (CMHDs) including anxiety, depression and obsessive-compulsive disorder are linked to cognitive decline and higher risk for dementia. Incidence of such psychiatric conditions are higher in populations with ID. This study considered the potential influence of CMHDs on cognitive ability and whether this is related to clinical signs of AD in DS.

Methods 111 individuals with no dementia diagnosis were selected from a longitudinal Down syndrome cohort. 31 of these individuals were affected by a CMHD, while 80 were not. We analysed changes in cognitive outcomes over two time points, comparing between the affected and unaffected groups using regression models using age, gender, APOE status and level of intellectual disability as predictors.

Results There was a significant association between CMHDs and poorer performance in a visual memory task ($p=.006$). There was a non-significant trend between informant-rated decline over time and CMHD diagnosis ($p=.070$).

Conclusions We found that CMHDs have a negative cognitive effect on visual memory. Our results highlight the importance of considering the effects of CMHDs on cognitive ability, particularly when diagnosing AD in DS.

From Science to Practice The potential impact of CMHDs on cognitive performance should be taken into account during assessment and diagnosis of AD in DS. Recognition of the negative effects of CMHDs can help to ensure that needs are accurately identified, and support is appropriately targeted for individuals with DS in order to improve quality of life.

Inventory for supported psychological evaluation (iSpe) – a research-based innovation project

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Keywords Digital assessment, Depression, Mental disorders, Communication, Innovation

Background Functional communication challenges can be a product of several diagnosis, including learning disabilities, autism, drug use disorders, dementia or schizophrenia. These groups have high prevalence's of mental disorders, but less access to quality mental health services and care. The iSpe project has developed a web-based prototype for the examination of depression, based on the idea of a communication supported psychological evaluation.

Methods The iSpe integrates easily understood animations and innovative response options. Several configurations can be made to the module, which makes it possible to individualize the assessment for optimal user participation and coping. A qualitative evaluation with nine people age 8 to 46 years with and without learning disabilities or autism was carried out as part of the development. Two participant were previously diagnosed with depression.

Results/Aims The evaluation showed that the application helped the participants to understand and convey complex emotional concepts and thoughts, such as depressed mood, self-esteem, worthlessness and guilt, fatigue, and thoughts of death in the diagnostic process. The participant with depression were identified with the iSpe. For three younger participants the animations functioned as starting conversation about thoughts and feelings. One participant stated: "It is much easier to tell about my feelings when I don't have to find theirs words".

Conclusions Preliminary findings from the development of the iSpe has shown its potential for further development. The next step is to investigate the generality, feasibility and validity of the iSpe as a digital self-reporting solution through a proof-of-concept project.

From Science to Practise The iSpe can bridge the gap between people who have trouble communicating mental health need and the services surrounding them. The iSpe may empower patients' health literacy and promote patients' participation in the mental health assessment.

Measuring stress levels: suitability of self-report stress measures for people with MID/BIF

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Keywords stress, state anxiety, self-report measures, mild intellectual disabilities, borderline intellectual functioning

Background Stress is a major contributor to the development of psychopathology and detrimental physical conditions. Persons with intellectual disabilities are more susceptible to the adverse impact of stress. Timely recognition of stress-related problems is therefore essential. Self-report measures are necessary to gain insight in the individual's perception of stress. Obtaining self-reported assessments for persons with mild intellectual disabilities (MID) or borderline intellectual functioning (BIF) appears to be feasible, when the measures are attuned to their capabilities.

Methods A scoping review was conducted to identify self-report stress measures that fit our purpose. The literature was searched for information on each measure's psychometric quality, assessment procedure details, and suitability for adults with MID. To gain a further understanding into the factors that determine 'MID-inclusivity', experts in the field of ID research were consulted.

Results A total of 13 self-reported stress measures met the final inclusion criteria, of which three were developed specifically for assessing stress in adults with MID. The abovementioned characteristics were reported for each included self-report stress measure. Results from the expert consultation were used to further refine the descriptions.

Conclusions The ID-inclusivity of the included measures appeared to be questionable, even for the ID-specific measures. Implications for the use and development of self-report stress measures are discussed.

From Science to Practise Stress levels are major determinants of health and wellbeing in the lives of persons with MID and BIF. They should be routinely assessed, especially when evaluating interventions and support needs. This requires measures not only to be scientifically sound, but also tailored to the possibilities of persons to self-report their experiences.

[Topic: Challenging Behaviour](#)

Inclusion and Participation of people with intellectual disability and challenging behaviour

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Keywords Challenging Behavior, Inclusion, Society and Community, Mental Disorders

Background Studies on participation in communal life of people with intellectual disabilities and challenging behaviour (CB) are sparse as shown in a recent international literature review (Markowitz, Wolf, Lang, Arndt, & Scherer, 2021).

Methods The presented data depicts the first Bavarian-wide standardised data-collection focused on inclusion of people with intellectual disability and CB (N= 2334) currently living in residential homes (N = 53). The study aims to highlight communal participation of residents of homes for persons with intellectual disability and CB. For this purpose, employees of said institutions were asked about the level of participation of the target group.

Results/Aims Seventy-two percent (n=1669) of residents of homes assessed are given the chance to attend the 'second-labour-market'. The majority of institutions highlight the advantages of access to work. Positive effects include an increase in self-efficacy and a reduction in challenging behaviour.

Ninety-one percent (n=48) of homes offer activities within their living environment., whereas 62 % (n=33) enable residents to participate in activities in the community. The use of daily services is open to residents of 74 % (n=39) of homes, and 89% (n=47) of institutions reinforce access to support services within the community.

In terms of self-determined life in an institutional context, people with ID and CB are mostly given the opportunity for self-care while restrictions are particularly evident in self-organisation of daily life, privacy and use of media.

Conclusions The findings can be implemented in guidelines for the practice of services.

From Science to Practise Especially regarding requirements of CRPD and BTHG for a stronger community-based approach of the care setting, these results provide insight into the poorly explored research topic of living conditions in institutions for people with intellectual disability and CB.

Measures preventing Challenging Behaviour of adults with intellectual disability in Swiss residential institutions

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Background Persons with intellectual disability are at greater risk for developing comorbidities, therefore psychiatric conditions are more common in this group than within the general population. Present results originate from the empirical study 'Challenging Behaviour (CB) of Adults with intellectual disability in Swiss

Institutional Settings' and focus on measures to prevent the emergence of CB. The study, funded by the Swiss National Science Foundation, aims at generating a good practice-model for the management of CB within institutional settings.

Methods A mixed methods approach was applied, including standardised online questionnaires, focus group discussions, qualitative interviews, and video analysis to gather multi-perspective data on measures preventing CB. At different stages, the sample included managing directors of residential institutions, primary care workers, multi-disciplinary care teams as well as persons with intellectual disability and CB. Data was analysed using descriptive and bivariate statistics respectively qualitative content analysis.

Results/Aims Among the sample of persons with intellectual disability, a substantial part was diagnosed with a psychiatric comorbidity. The results show a broad variety of measures preventing CB, however, the preventive measures differ from one sample group to another. The results demonstrate the need for preventive measures to be specifically adapted to particular persons and their needs. An overview of preventive measures will be presented with an emphasis on data originating from persons with intellectual disability.

Conclusions The view of adults with intellectual disability emphasizes the importance of factors such as interactive skills as well as trustful relationships with care staff in order to prevent CB.

From Science to Practise A context-oriented good practice-model for the practical management of CB in Swiss residential institutions was developed, intending to increase the quality of life of persons with intellectual disability.

Supporting adults with intellectual disability and challenging behaviour in Swiss residential care: Towards an ecological systems approach.

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Keywords Challenging Behaviour Management, Ecological Systems Approach, Good Practice, Institutional Care, Intellectual Disability

Background Challenging behaviour (CB) such as aggression, self-injury, or property destruction is a common phenomenon in roughly one third of Swiss residential institutions for adults with intellectual disability. From an ecological systems perspective, CB are seen as products of interactions between the individual and its context. They thus present challenges for the persons showing CB as well as for their care staff. A three-year national empirical study aimed at a profound description of CB and its related factors.

Methods A mixed methods approach including standardized questionnaires, videography, interviews and focus groups with the involved adults with ID, their care staff as well as their relatives, led to the development of empirically based types of interactions between the adults needs and their living setting. Furthermore, a good practice model that offers support for adequate interventions in residential care settings was developed - based on beneficial and obstructive factors concerning CB extracted from the data.

Results/Aims The four empirically based types as well as the good practice model will be presented.

Conclusions Good practice interventions concerning CB implicate complex processes and need to focus on different levels and actors in a coordinated way in order to provide successful support.

From Science to Practise Both, the empirically based types as well as the good practice model, support persons involved in the management of CB within residential care settings and thus, aim to increase the quality of life of persons with intellectual disability.

Topic: [Physical Health / Health Inequalities](#)

Increased susceptibility of Covid-19 diagnosis in Down syndrome compared to the general population

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Keywords Down syndrome, Covid-19, susceptibility, risk of infection, chronic respiratory disease

Background People with Down syndrome (DS) have been disproportionately affected by Covid-19 with higher rates of hospitalisation and mortality. However, whether those with DS are at increased risk of Covid-19 infection remains to be explored. We examined susceptibility of Covid-19 diagnosis in DS compared to the general population.

Methods Our sample consisted of anonymised primary care data from the electronic health records of 43,716 individuals (8881 DS and 34835 controls) from the Clinical Practice Research Datalink (CPRD) Aurum database in the UK.

Results/Aims People with DS were more likely to be diagnosed with Covid-19 (OR 1.51 [1.33 - 1.71 95% CI], $p < 0.001$). We found a significant interaction between people with DS and a chronic respiratory disease diagnosis excluding

asthma and increased odds of a Covid-19 diagnosis (OR 1.68 [1.05 - 2.69 95% CI], $p = 0.03$) while adjusting for a number of DS specific and non-specific comorbidities. In a sub-analysis of 3940 individuals with data on living situation, this interaction remained even after accounting for the impact of living in residential or care settings.

Conclusions People with DS and a chronic respiratory disease diagnosis excluding asthma are more susceptible to being diagnosed with Covid-19.

From Science to Practise People with Ds are more susceptible to Covid-19 infection and have poorer outcomes compared to the general population. It is critical that people with DS and a chronic respiratory disease diagnosis are sufficiently shielded and prioritised for vaccination for future waves of Covid-19 or similar pandemics since studies have reported increased severity of Covid-19.

Topic: Profound Intellectual and Multiple Disabilities

Self-Determination of Individuals With Extensive and Complex Support Needs

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Keywords people with severe or profound intellectual and multiple disabilities, self-determination, first-degree relatives, grounded theory with sensitizing concepts

Background Self-determination is seen as important for subjective well-being and quality of life. However, the meaning of this psychological construct for people with the most severe disabilities remains elusive.

Methods This study explored first-degree relatives' perceptions on the meaning and support for self-determination of 11 people with severe or profound intellectual and multiple disabilities. Semi-structured interviews were analyzed following a grounded theory approach with "autonomy", "competence", and "relatedness" as sensitizing concepts.

Results/Aims that autonomy, competence, and relatedness held important meaning for their family member, although it mainly lay in very small, seemingly inconspicuous things that were often of insignificant value to others. In addition, descriptions were dependent upon person, circumstances, and environmental support. Processes underpinning the support for self-determination were conceptually modelled to represent the challenges relatives experienced in noticing, clarifying and responding to their family member' needs signals.

Conclusions The understanding of meaningful self-determination for people with the most severe disabilities remains challenging, because it requires intimate, first-hand knowledge of the person involved. The process model of self-determination support – based on the knowledge and experiences of relatives – may therefore provide a basis for guidance of both relatives and healthcare professionals.

From Science to Practise To support healthcare professionals in their knowledge about self-determination, relatives may be more involved as equal partner in education programs and the ‘client-relative- professional’ triad. For example, healthcare professionals can empower relatives more to share their exceptional expertise about their family member’ unique intrinsic psychological needs and the facilitators that are helpful in understanding and supporting them.

The ‘DHG standards’ for supporting participation in case of persons with profound intellectual and multiple disabilities

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Background Persons with profound intellectual and multiple disabilities, e.g. persons with intellectual disability/challenging behavior, are particularly affected by difficulties and restrictions concerning the implementation of full participation. Although the group of people is very heterogeneous, they all have in common that they cannot speak for themselves or can only do so to a limited extent and need advocacy support in order to assert their rights and interests.

Methods As a result of more than two years of discussion the German association “Deutsche Heilpädagogische Gesellschaft” (DHG) has developed and published with a circle of supporters as well as expert discussions the so-called ‘DHG standards’ in terms of guiding goals and recommendations for action for professionals and services in disability assistance.

Results/Aims The ‘DHG standards’ for participation in complex support needs are to be understood as a contribution to the process of shaping,

concretising and implementing participation in professional, legal and socio-political terms.

Conclusions With its standards on participation, the DHG initially focuses on five fields of action: Participation and Assistance; Participation and Care; Individual Participation Planning and Participation Management; Participation in Social Spaces; Participation in Working Life.

From Science to Practise The standards on participation can be guidelines as means to advance of the target group to implement good practice and to enrich state of the science practice in other disciplines (e. g. medicine, nursing).

Topic: Spirituality

Spirituality and Quality of Life in Individuals who are Deaf and have intellectual disabilities

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Keywords quality of life, spirituality, deafness, ID, therapeutic living communities

Background While positive contributions of spirituality and religion on quality of life are confirmed by a growing body of evidence, only limited research has involved people with intellectual disabilities and so far, no deaf individuals with intellectual disabilities. This study aims at understanding the role of spirituality and religion in people with intellectual disabilities and deafness living in three therapeutic living communities. Those communities are characterized by their focus on social communication assured through the constant use of individually adapted sign language.

Methods 41 individuals (mean age: 46.93, female: 43.9%) with prelingual deafness and mild to moderate ID participated. Through employing measures adapted to the specific cognitive and linguistic needs (EUROHIS-QOL-ESL), self-reported information about quality of life as well as perceptions about faith and spiritual practice could be reliably obtained. Additionally, proxy ratings on the participants' quality of life as well as their spirituality were acquired.

Results The individuals' ratings of their faith ($r = .366$; $p = .019$) and spiritual practices ($r = .412$; $r = .007$;) correlate positively with their overall quality of life. Quality of life and spirituality were significantly rated higher by the individuals themselves, than by their proxies ($p < .001$). Excerpts from qualitative interviews illustrate the individuals' religious and spiritual understandings and practices.

Conclusions Personal faith and participating in spiritual practices are positively related to self-reported quality of life in deaf individuals with intellectual disabilities.

From Science to Practise Spirituality should be considered as a valuable dimension of life and be made accessible in services for all people with intellectual disabilities.

Topic: Emotional Development

The importance of the emotional development in the musictherapy with individuals with intellectual disability

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Keywords: Musictherapy, Emotional development, SEED, EBQ-Instrument

Background: Music offers one of the best ways to express feelings.

Musictherapy works with people that have problems to express or to perceive them. People with intellectual disability suffer from this condition and they need something or someone to perceive or/and express them. To plan the right way to do this is essential to consider the emotional development state of this kind of clients.

In the following abstract will be shown a case from the practice, that demonstrate the importance of the assessment of the emotional development. It will be shown that musictherapy interventions are more effective if the emotional development has been assessed in the right way, and that positive behavioral changes and improvements are possible.

Method The emotional development of the client has been assessed with the "Skala der Emotionalen Entwicklung - Diagnostik" (SEED; Sappok, Zepperitz, Barrett & Dosen, 2018). The musictherapy intervention follows the EBQ-Instrument method (Schumacher, Calvet & Reimer 2018).

Results/Aim This case will show that, especially with difficult clients, this way of operate could be succesfull and that the client could benefit in everyday life from this, in terms of feelings regulation and interaction with others.

Conclusions If the emotional development has been assessed in the right phase, the first person who benefits from this is the client. But of course it makes easier for the therapist to work with them.

From science to practice Working with these two methods (SEED and EBQ), shows how they are scientifically worthwhile, because the results are that people with intellectual disability are more interactive and they can manage alone and quicker to regulate their feelings

The social-emotional functioning of young children with a significant cognitive and motor developmental delay

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Background Children with a significant cognitive and motor developmental delay (SDD) are vulnerable for the development of (future) behavioral and mental health problems. To support children within this target group, an adequate assessment of their social-emotional development is necessary.

Methods Semi-structured interviews with one or more primary caregiver(s) of 45 children were conducted and analyzed on 13 domains of social-emotional functioning, according to the Scale for Emotional Development - Revised (SED-R). The scoring system was slightly adapted in order to elucidate more subtle differences between children. For 25 children, yearly measures over a two-year period were analyzed (three time points).

Results/Aims A general delayed social-emotional development was found, with children functioning within different phases across domains and certain domains generally showing higher or lower scores. Also, a lot of variation in individual and group patterns of change across the two-year period was evident.

Conclusions Charting the social-emotional development in this target group is challenging and requires further in-depth analysis of individual trajectories as well as more fine-grained and long-term data collection.

From Science to Practice This study confirms that the SED-R can be used as a reflection tool to assess the basic social and emotional needs of children with SDD. By gaining detailed knowledge of children's functioning within different subdomains, the caregivers' support approach can be adapted dynamically across different situations, taking specific strengths and weaknesses of the child into consideration. Further, considering that individual children can show stability, increases and even (temporary) decreases variedly across different domains and time points, this study shows that frequent re-assessment may be appropriate to ensure an optimal environment for the children's learning and well-being.

Topic: Prevention

Triggers for dysfunctional mental health of mothers raising a child with disabilities – Towards an intervention model

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Keywords Mental health, Mothers, Multiple disabilities, Bronfenbrenner, Auto-Ethnography

Background Risks for mental health dysfunction are often a direct result of strained relationship experiences of interactions within the social environment as defined by Bronfenbrenner. Subsequent social exclusion and stigmatization have been found to increase feelings of depression, guilt, helplessness and suicide and infanticide ideation.

This paper explores the environmental triggers causing dysfunctional interaction behavior of a mother caring for her brain-injured child's development (birth to 10 years). The focus is on conceptualizing a framework of intervention strategies in response to these triggers, moderating positive parenting and functional interpersonal relationships.

Methods This qualitative study uses auto-ethnography as methodology and the theoretical frame is Bronfenbrenner's ecological model as it relates to multi-dimensional interaction. Reflective journaling serves as data source to render narratives detailing the findings.

Results/Aims The purpose is to provide a personalized reflective account of one mother's journey towards understanding how interaction with her environment impacts her mental health and parenting behavior. The study is relevant as the process utilized by the subject-researcher provides a method of trigger self-examination and strategy identification to improve current practice.

Conclusions Various triggers or moderators, such as dismissive grandparents or misinformed teachers that may contribute to mental dysfunction, were identified at each level of Bronfenbrenner's ecological model. A conceptual framework is postulated to guide the use of positive strategies in response to these triggers.

From Science to Practice Positive interaction with triggers are operationalized in the form of strategies accessed through a Mobile Phone App to support and empower mothers to stay mentally strong and develop positive relationships.

[Topic: Empowerment and Independence](#)

WIELD 2: Using a picture book to improve epilepsy management for people with intellectual disabilities

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Keywords Health Education, Communication, Chronic conditions, Epilepsy

Background One in five people with intellectual disabilities (ID) has epilepsy. Previous research suggests that an intervention using the Beyond Words 'Getting on with Epilepsy' picture book may improve epilepsy management and quality of life. WIELD2 draws on process evaluation methodology to evaluate the key features of the intervention and how best to deliver the intervention in routine care.

Method Twenty adults with intellectual disabilities and epilepsy used the book in a video-recorded session with a clinician, followed by a 4-week period of home-use. Interviews with participants (n=18) and clinicians (n=5) were then conducted to explore people's experience of using the book.

Results/Aims Four collections were identified through conversation analysis of the intervention session and were triangulated with thematic analysis of the interviews: Understanding epilepsy; Relating to own experience; Information sharing and education; Developing understanding and addressing misunderstandings. Three 'levels' of book use (describing the pictures; inferring character's feelings; relating to own experience) were identified along with techniques for supporting participants to access all these levels and maximise the book's benefits.

Conclusions Guidance for using 'Getting on with Epilepsy' is being produced, to improve epilepsy management and quality of life for people with intellectual disabilities.

From Science to Practice Improve understanding, empowered, better life.

[Solicited Symposia](#) [English and German Online](#)

[Topic: Inclusion, Society and Community \(SoS-21 E/OL\)](#)

COVID-19 and People with Intellectual Disabilities in the UK – what happened?

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Background The global pandemic has dominated societies since January 2020. Over 140,000,000 people have been infected with the virus and over three million have died. The infection has had a disproportionate impact on specific groups of people and especially those with intellectual disabilities.

Method The presentation explores how people with intellectual disabilities were protected from infection, the decisions on resuscitation and the

vaccination programme. What lessons we should learn to prepare for future pandemics and to protect people from harm.

Results/Aims The impacts of the pandemic in the UK have been extreme and intense since it first appeared in the country that has recorded one of the highest death rates in Europe. The death rate among adults with intellectual disabilities in the UK has been more than double that in the general population with rates of six times greater reported. People with intellectual disabilities have died at younger ages than in the general population. People with Down syndrome have had a greater level of mortality. Many were subjected to decisions to withdraw resuscitation based on the presence of an intellectual disability. The vaccination programme has been disproportionate in vaccinating those with intellectual disabilities without prioritising this at-risk group.

Conclusion People with intellectual disability have suffered disproportionately more than others in society due to infection and the implementation of the vaccine programme. Thorough review of the experience is essential in preparation for future pandemics and how they will impact on people with intellectual disabilities.

From science to practice Learning from the effects of the pandemic will be translated in to enhanced public health measures to protect people

Keywords Intellectual disability; COVID-19; pandemic; vaccination

COVID-19 pandemic – effects and challenges in people with intellectual disabilities

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Background The COVID-19 pandemic has had a broad spectrum of direct (e. g. hospital admissions, death) and indirect (e. g. lockdowns, loss of jobs) consequences. COVID-19 strikes societal, economic, social, emotional and health-related consequences. People with intellectual and other disabilities are confronted with far reaching impacts. These consequences jeopardize their inclusion and boost their social exclusion. Nevertheless their fate is often neglected in the public debate.

The symposium focuses on the impact of the pandemic on people with intellectual disabilities. It shines a light on selected aspects of the pandemic in this vulnerable group bringing together experiences from three countries.

Methods Practical Experiences and scientific results from the UK, US and Germany are considered.

Results/Aims There are similarities and specific differences between the countries regarding the impacts on people with intellectual disabilities.

Conclusions Differences may be explained by distinct qualities of respective social and health care systems.

From Science to Practise It is hoped the discussion will show ways to ameliorate negative effects in service providing etc. The main objective is promoting social inclusion and avoiding social exclusion of people with intellectual and other disabilities.

Keywords Covid-19, inclusion, exclusion, health care system, social care system

How to Address and Better Prepare for Pandemic Related Trauma Experienced by People with Intellectual Disabilities

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National Association for the Dually Diagnosed

Background The pandemic created significant disruption in our social and psychological world, impacting major aspects of life. For many individuals with intellectual disabilities, these disruptions were traumatic, difficult to comprehend and involved major loss and ongoing uncertainty.

Methods Using examples from interviews with clinical experts, I will share insights gained over this last year. I will also discuss ideas on how to change clinical and support approaches to be better prepared to address the emerging and complex needs of individuals with intellectual disabilities, in the event of a future pandemic or similar catastrophe.

Results/Aims To better understand the impact of the nuances of pandemic-related trauma on people with intellectual disabilities and to enrich and expand treatment modalities

Conclusions We have learned a great deal over the last year about the impact of social isolation, routine disruption, loss and uncertainty on individuals with intellectual disabilities and how that impact differs from people who do not experience cognitive challenges in the same way. We now have the opportunity to refine our practices accordingly.

From Science to Practise Through continued clinical observations and structured research, we will learn in more depth about the complexities and interacting layers of trauma resulting from the extraordinary experience of living through the pandemic. This new knowledge will guide us in developing increasingly effective treatment approaches, increasing our capacity to meet the mental health needs of the people we support.

Keywords Trauma, Psycho-Social Impact, Mental Health

Impact of COVID-19 on families with young children with developmental disabilities

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Background The recent pandemic has impacted the health wellbeing of a significant proportion of the population. Vulnerable groups such as families with children with developmental disabilities may be disproportionately affected by pause in services they rely on for support.

Aims An anonymised survey of parents of preschoolers to identify areas of impact of the pandemic.

Results Eighty-five parents from 4 areas in England responded. They reported that both they and their children had suffered as a result of the social distancing rules and the consequent social isolation. They found that remote consultations were not useful and difficult to follow with a child who might be unable to tolerate the digital platforms. They did like welfare checks however. They were particularly concerned about the loss of skills as the children remained at home and lost schooling. They were not overtly concerned with risk related to infection but were preoccupied with the longer term impacts such as loss of work and reduced income or availability of services in a situation where the economy might be affected to a significant extent.

Conclusion Vulnerable populations may require additional supports and their needs should be considered from the outset in preparations for future health emergencies including the utility of telehealth.

From Science to Practice Its hoped to find new and creative options to support the families with children with developmental disabilities.

Keywords Covid-19, pandemic, children, society, developmental disabilities

Impact of the COVID-19 pandemic on people with disabilities in Germany - Results of an online-based survey

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Background The COVID-19 pandemic has had and has many consequences in general. COVID-19 strikes societal, economic, social, emotional, and health-related consequences. Especially for people with intellectual and other disabilities who are confronted with far-reaching impacts. Nevertheless, their plight is often neglected in the public debate.

To identify the most prominent effects of the pandemic and their respective interrelation the German Association for Rehabilitation conducted a broadly

conceived survey regarding the consequences for people with disabilities or chronic illnesses in Germany in November/December 2020.

Methods Online questionnaires were used to get the views of people with disabilities and chronic illnesses, their relatives, care takers, and personal supporters, service providers, state authorities, and representatives of the civil society. The questions covered many aspects: work situation, schooling, health services, social situation, social contacts, emotional health, general health aspects, experiences with digital media etc. The participants were asked for proposals to compensate against negative impacts. To allow the focus on people with intellectual disability to be embedded into a broader frame.

Results More than 6000 people took part. The survey revealed several wide ranging consequences for people with disabilities, their relatives, service providers and authorities responsible for financing social care. The social inclusion of people with disabilities is heavily jeopardized by the pandemic-driven measures and sanctions from authorities, especially lockdown, restrictions of contact, and pause of services. The participants delivered many useful suggestions and proposals to lessen the impact of COVID on people with intellectual disabilities.

Conclusions It is necessary to take appropriate action by the German legislator, local authorities, service providers etc. to compensate the manifold and often deep-reaching effects of the pandemic.

From Science to Practice It is hoped a broadly based discussion in Germany will result in measures very. The main objective is promoting social inclusion and avoiding social exclusion of people with intellectual and other disabilities.

Keywords Disabilities, chronic illnesses, pandemic, Covid-19

[Co Productive Symposia English and German Online](#)

[Topic: Inclusion Society and Community \(CpS-3 E/OL\)](#)

Beyond Words- tools for empowering people

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1Beyond Words / Kingston & St George's University (UK), 2Kingston & St George's University (UK), 3Christliches Sozialwerk gGmbH (Germany), 4Respond (UK).

Background People with intellectual disabilities are often excluded from understanding issues that affect their lives (such as bereavement, abuse or Covid). Books Beyond Words are wordless narratives that seek to empower people by enabling them to understand what is happening in their lives.

Aim To introduce and demonstrate the use of wordless narrative to empower service users to take ownership of their own life stories and to support their mental health, and to support their inclusion in everyday life.

Method In this symposium, we will give face to face and video demonstrations of the practical use of pictorial scenarios one to one and in groups. There will be opportunity for discussion about the range of resources available in print and digitally and of opportunities to tailor them for one's own local needs; and handouts summarizing research evidence for efficacy. All resources are co-developed with people with intellectual disabilities, and two groups of people with intellectual disabilities (one from the UK, one from East Germany) will be involved in the demonstrations

Results An understanding of visual literacy and its pedagogical importance in enabling service users to play a fuller part in their own health and wellbeing

From Science to Practice Books Beyond Words are wordless narratives that have been shown to empower people to take control of their own health and well-being. For example, one of our pictorial Covid- resources have been downloaded 100,000 times.

Keywords Wordless narrative, Empower, Pedagogy, Trauma, Co-production

Supporting persons with Intellectual Disability participating in crisis

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Keywords COVID-19, Inclusion, participation, human rights, best practice

Background COVID-19 pandemic, personal protection measures as well as governmental restriction measures challenged social service organisations their employees as well as their clients.

Methods Through in depth interviews we gained insights into the experiences, challenges faced by people with intellectual disability. We also examined social care provision and leadership during the COVID-19 pandemic..

Results/Aims This coproductive Symposium from "Lebenshilfe Tirol" and University of Innsbruck examined issues of inclusion, society and community, before addressing ethics and human rights and how employees strongly identified with organisational values and norms.. "Lebenshilfe". Flat hierarchies, decision-making and assumption of responsibility as well as open communication serve as the basis for coping with the pandemic. Employees were found to have confidence in the measures taken by management and executives. Fundamental to this co-production is to actively include people with intellectual disability in crisis management plans and to

resource it. As the “Lebenshilfe” is meant to fulfil the responsibility of community, persons with intellectual disability are included in communication and Information processes and dissemination. Examples of Information dissemination are information sheets in simple language and pictograms for the instruction of Personal Protective Equipment (PPE). A “SprecherInnensystem” represents the tool guaranteeing clients direct communication with the chief executive.

Conclusions Crisis management of “Lebenshilfe Tirol” aimed at including persons with intellectual disability in communication, Information, safety was characterised by clear and centralized information dissemination as well as continuous regular communication with people with intellectual disability, relatives and those involved in their Care at all levels.

From Science to Practise Clear and timely Information dissemination and communication are crucial during crisis as well as in daily interaction with clients, as well as at all levels of organisations in health care sector.

Onsite

Topic: Physical Health / Health Inequalities (CpS-1 E/OS)

Addressing Sleep Disorders in Intellectual Disability

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Background Sleep disorders affect the duration, quality and timing of sleep, and are present in at least

32% of adults with intellectual disability. When untreated, sleep disorders adversely affect: overall health, daytime functioning, challenging behaviours, and increase carer burden. Despite their deleterious effects, sleep disorders are frequently overlooked, and there is a perception that they cannot be improved.

Methods This symposium will be delivered by consultants in sleep psychiatry (DO’R), sleep neurology (AN) and mental health in intellectual disabilities (KC), who have experience of working across NHS services (UK) to assesses, investigate and treat sleep disorders.

Results/Aims Over four presentations, we aim to give an overview of sleep disorders in adults with intellectual disability, focusing on the assessment, investigation and treatment of insomnia and delayed sleep wake phase disorder. Parents of an adult with intellectual disability will discuss the impact of sleep disorders on their daughter and family, and what it meant to have these addressed.

Conclusions Recognising and addressing sleep disorders can greatly improve the overall health, wellbeing and daytime function of adults with intellectual disability. Medical nihilism in this field should be confined to bedtime stories!

From Science

to Practise Addressing sleep disorders in adults with intellectual disability improves daytime functioning, quality of life, as well as physical and mental health co-morbidities.

Keywords Sleep disorders, insomnia, intellectual disability

Disclosures 1Disclosure DO'R, has received honoraria for lectures given to BAP and TEVA, 2Disclosure AN, has received honoraria for lectures given to TEVA.

Topic: Education and Employment (CpS-2 E/OS)

Co-presentation with people with intellectual disabilities , employment, education, inclusion

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Background

People with intellectual disability often experience mental illness more than the general population as a direct result of discrimination and lack of opportunities to engage in education, employment and with the society at large.

Methods This presentation describes three examples of co production aimed at empowering people with intellectual disability

1. Reasonably adjusted employment project
2. Training people with ID to become peer educators
3. Supporting people with ID to share their experiences during COVID 19 pandemic and producing and publishing these stories in a book.

Results/Aims The study reported on three successful projects engaging an international population with intellectual disability to demonstrate value driven co-production

Conclusions People with intellectual disability can learn, achieve and excel in any of the above project related activities when they are given the opportunity to do so.

From Science to Practise Science and research has evidenced that for maintaining good mental and physical wellbeing people needs to be able to engage in education, employment and socialisation.

These project show how with the right support and adjustments people with intellectual disability can live fulfilling lives and engage in valued activities.

Keywords Co-production/presentation, education, employment, inclusion

[Solicited Symposia English online](#)

[Symposia two \(SoS-22 E/OL\)](#)

[Topic: Communication](#)

Joint attention and shared enjoyment in storytelling for individuals with multiple disabilities

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1, 2, 3 Royal Dutch Kentalis, 3 University of Groningen

Keywords Multiple disabilities, storytelling, communication, parent support, staff training

Background A multi-sensory storytelling method as Sensory Enhanced Interactive Storytelling (SEIS-T) offers a useful framework to stimulate storytelling for children with Intellectual Disabilities and Hearing Impairment (IDHI) or Congenital Deafblindness (CDB) to stimulate interaction and communication. Previous studies of SEIS-T involving both target groups, revealed spontaneous occurrences of joint attention and shared enjoyment during some of the storytelling-sessions.

Methods In this study, a mixed design of qualitative and quantitative methods is used to get insight in specific story-elements and strategies that lead to shared enjoyment and joint attention between people with IDHI and DSL and their communication partners during SEIS-T storytelling activities. The study exists of a critical review of the literature, focus groups and a multiple-case experiment with 12 dyads.

Results/Aims The aim of the study is to get insight in the specific story-elements and strategies that lead to shared enjoyment and joint attention between people with IDHI and CDB and their communication partners.

Conclusions Research findings will be used to give communication partners more detailed instructions on how to interact during storytelling with the aim of promoting moments of shared enjoyment and joint attention.

From Science to Practise Sharing enjoyment during multi-sensory storytelling has been described as positive for the wellbeing and learning of persons with multiple disabilities. This study aims to contribute to the wellbeing and learning of these persons, as the results of this study will be used to develop instructions for parents and professional caregivers of people with IDHI and CDB on how to create moments of shared enjoyment within storytelling. In this presentation, examples will be shown of the use of SEIS-T stories in practice.

Enhancing the communication between individuals with multiple disabilities and their communication partners

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1,2,4 Royal Dutch Kentalis, 3,4 University of Groningen

Keywords Multiple disabilities, storytelling, communication, parent support, staff training

Background Creating meaningful interactions can be challenging for parents or professional caregivers of people with multiple disabilities, such as individuals with Intellectual Disabilities and Hearing Impairment (IDHI) or Congenital Deafblindness (CDB). Communication may be limited to the level of functional and daily needs, as communication breakdowns occur frequently and lead to frustration. Creating positive communicative interactions require specific skills, expertise and commitment from communication partners.

Methods Several case-experiments were conducted, focusing on improving communication between people with IDHI or CDB and their communication partners. The intervention approaches were aimed at supporting the partners with tools or a training. Two studies focused on the effects of Sensory Enhanced Sensory Story-Telling (SEIS-T) and one study on the effects of a training for communication partners with video-feedback. To test the effects of these interventions, interaction and communication patterns were analysed, communication abilities were rated, or the self-efficacy of communication partners was determined.

Results/Aims Data analysis revealed positive effects of SEIS-T on communication patterns for participants with IDHI and CDB. Training with video-feedback revealed improved self-efficacy of communication partners and higher rated communication abilities for some participants with CDB.

Conclusions SEIS-T can support communication partners of people with multiple disabilities to stimulate moments of positive contact. Video-feedback training is another means of supporting communication partners in stimulating interpersonal communication.

From Science to Practise Communication is necessary for participation and wellbeing. The three studies each contribute to both for people with multiple disabilities, by developing instructions, video- examples, online materials and staff-training for stimulating interpersonal communication between these people and their communication partners.

Effects of Sensory Enhanced Interactive Story Telling (SEIS- T) for individuals with multiple disabilities

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Keywords Multiple disabilities, storytelling, communication, parent support, staff training

Background Storytelling can provide positive interactions, promote language and communication skills, as well as social and emotional development. Adapted forms of storytelling are necessary to make storytelling more interesting and accessible for people with Intellectual Disabilities and Hearing Impairment. Therefore, the Sensory Enhanced Interactive Story Telling (SEIS- T) approach has been developed, based on scientific insights about interaction, communication and storytelling for this target group.

Methods Six children with IDHI participated in an effect study to test if there were differences between their communication patterns during regular storytelling sessions and during SEIS- T storytelling sessions. An event-sampling method was applied to analyse video of the regular storytelling sessions offered during a baseline phase and videos of the SEIS-T storytelling sessions during the intervention phase. The Nonoverlap of All Pairs technique was used to test differences between the baseline and intervention phases for each case.

Results/Aims Analysis of the videos revealed that the participants with IDHI were more involved in storybook reading during SEIS-T Stories compared to the regular storytelling sessions. Children communicated more actively. For example, more direct responses to the teacher were observed in four participants, such as replying to a question, and four participants showed more story-oriented initiatives during SEIS-T.

Conclusions The children communicated more and in a more varied way during storytelling with the SEIS-T approach than during the normal story. Engagement was high in all children. These are promising results for further application of SEIS-T to stimulate communication in children with IDHI.

From Science to Practise SEIS-T is developed out of clinical and educational practices for children with IDHI and builds an adjusted conversational space for interactive moments of storytelling.

Effects of 'Tell it!' on the communication abilities of individuals with Congenital Deafblindness

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1,2 University of Groningen, 2 Royal Dutch Kentalis

Keywords multiple disabilities, communication, parent support, staff training, effect study

Background Communication partners of individuals with Intellectual Disabilities and sensory impairments often have difficulties with recognizing and understanding their communicative signals. As a consequence, these individuals may have limited opportunities to express themselves. The intervention Tell it! aims to support communication partners in stimulating communication abilities of individuals with intellectual disability and Congenital Deafblindness (ID&CDB).

Methods This study examined the effects of 'Tell It!' for eight individuals with ID&CDB on the communication abilities of these individuals such as perceived by their communication partners, and the self-efficacy of the partners. Sixteen partners received three educational sessions and seven video-feedback sessions by a communication coach. They completed four questionnaires at four measurement points in the baseline phase and three measurement points during the intervention phase.

Results/Aims At the end of the intervention phase the mean score on the Communication Abilities Questionnaire and Influence in Communication Questionnaire both appeared higher for all participants with intellectual disabilities and CDB, but this was not significant. For three out of eight participants a higher communication level was rated on the Communication Matrix at the end of the intervention phase and for five out of eight, also a higher variation in communicative behaviours. The mean rating of self-efficacy of the communication partners was significantly higher at the end of the intervention phase.

Conclusions Communication partners reported feeling more competent in communicating with participants with ID&CDB after the intervention. However, only for some of these participants their communication abilities were rated higher at the end of the intervention.

From Science to Practise This study tested a training for communication partners of people with multiple disabilities that aimed to contribute to their participation and self-determination.

Topic: Challenging Behaviour
Symposia three (SoS-23 E/OL)

Views and Experiences from Multiple Stakeholders of Intensive Support Teams

1Leila Hamza

1Division of Psychiatry, University College London, UK

Keywords Intellectual disability, challenging behaviour, intensive support

Background There is limited evidence about the experiences of stakeholders engaged with intensive support teams. We will report on a qualitative exploration of the views of multiple groups.

Methods Semi-structured interviews/focus groups were conducted with individuals with intellectual disability, family carers, paid carers, IST managers and staff in 10 ISTs across England. Data were analysed using thematic analysis.

Results/Aims Overall, stakeholders reported similar experience irrespective of the operational IST model. Person centred care, negotiation of treatment goals and resource are main areas of concern.

Conclusions Expectations of care vary according to stakeholders.

From Science to Practise The study indicates the operational model of IST is not connected to the care provided to individuals with intellectual disability.

Psychosocial interventions for aggression in people with intellectual disabilities

David Prior¹, Soe Win², Ian Hall¹, Afia Ali³, Angela Hassiotis³

1 East London NHS Foundation Trust, UK 2 North East London NHS Foundation Trust, UK

3 University College London, UK

Keywords Behavioural, Cognitive, Interventions, Challenging Behaviour

Background Outwardly directed aggressive behaviour is a significant problem in the care of people with intellectual disabilities. We updated our Cochrane review including a meta-analysis to produce evidence for clinical care.

Methods We followed standard Cochrane review methodology to carry out searches of databases and grey literature. Two review authors independently identified studies and extracted and assessed the quality of the data

Results We will report on study quality and meta-analysis findings

Conclusions Previous versions of this review reported limited evidence due to the lack of randomised controlled trials. However, there has now been a significant increase in trials and therefore we will be better placed to identify effective interventions.

From Science to Practise the Cochrane review findings will have direct impact on intervention delivery as we will be able to make specific claims about effectiveness.

Crisis care for people with intellectual disabilities who display challenging behaviour

1Angela Hassiotis, 2David Prior, 2Ian Hall, 1Leila Hamza,

1Division of Psychiatry, University College London, UK 2Hackney Integrated Learning Disability Service, East London Foundation Trust, UK

Keywords crisis care, intensive support teams, effectiveness

Background Intensive support teams (IST) have had a long history in supporting people with intellectual disabilities who display challenging behaviour in the community following deinstitutionalisation. However, there has not been a systematic investigation of those teams despite several policy drivers to develop an effective acute care model for this population group.

Methods The symposium will comprise of four related studies including a systematic review and 3 presentations (quantitative and qualitative) relating to an NIHR funded mixed methods study of intensive support teams in England, UK.

Results/Aims The presenters will discuss an updated Cochrane review on psychosocial interventions for challenging behaviour, and the findings from the clinical and cost effectiveness of ISTs as well as the stakeholder experience of the care they have received.

Conclusions ISTs are essential in the care of people with intellectual disabilities who face a crisis due to challenging behaviour. The symposium will establish new information relating to existing service provision which will be of interest to practitioners and researchers internationally.

From Science to Practise The systematic review and meta-analysis as well as the findings from the systematic investigation of ISTs will impact the care adults with intellectual disabilities receive and inform further policy and commissioning of services for challenging behaviour.

Cost effectiveness of Intensive Support Teams for challenging behaviour

1Angela Hassiotis

1Division of Psychiatry, University College, UK

Keywords Adults, cost effectiveness, challenging behaviour, intensive support

Background There is inconsistent evidence on the cost effectiveness of intensive support teams for people with intellectual disabilities who display challenging behaviour. The limited evidence is of local projects which may not be representative of the operation of such teams elsewhere. This is the first study internationally to estimate costs of intensive support teams in England.

Methods For the cost effectiveness analysis, we will take two perspectives: (a) Health and social care perspective.

(b) A wider societal perspective

Under each of these perspectives we will include the IST service model costs for the two different service types.

Results/Aims We have yet to finalise the health economic analysis which is based on service use costs of 226 participants from 21 intensive support teams in England.

Conclusions Findings including service use will be made available at the time of the presentation including the relative costs of the 2 service models.

From Science to Practise Findings on cost effectiveness of intensive support teams will give commissioners and NHS England a clearer direction about the impact of such services on the wellbeing of people with intellectual disabilities and of their carers.

Clinical effectiveness of Intensive Support Teams for challenging behaviour

1 Ian Hall

1Hackney Integrated Learning Disability Service, East London Foundation Trust, UK

Keywords Adults, intellectual disability, challenging behaviour, intensive support

Background There is limited evidence about the clinical effectiveness of intensive support teams (ISTs), specialist teams to support individuals with intellectual disability and challenging behaviour stay in their local communities. The study used quantitative methods to evaluate the clinical effectiveness between the two models.

Methods An observational study was conducted with adults with intellectual disability receiving care from 21 ISTs across England (N=226). Individuals were followed-up at 9-months. The main outcome was decrease in challenging behaviour as measured by the Aberrant Behaviour Checklist- Community

Results/Aims Challenging behaviour was decreased in individuals with intellectual disability. There is no difference in clinical effectiveness of the two models of ISTs in England: integrated in community intellectual disability service and stand-alone service

Conclusions The impact of specialist support to individuals with intellectual disability was emphasised by reduction of challenging behaviour and improved mental health outcomes.

From Science to Practise From these findings, allocation of resources and implementation of ISTs in the NHS should not prioritise one model over the other, but rather fit in best with existing local resources, as model type does not appear to impact upon its effectiveness.

Solicited Symposia English onsite

Topic: Child and Adolescent

Symposia one (SoS-1 E/OS)

Treatment at your doorstep : Different treatments in a safe and homely atmosphere setting

2KC Dekker

2Youz/de Banjaard Parnassia Groep

Keywords Children, Innovative Care, Psychiatric treatment

Background The Banjaard is a multi-disciplinary clinic with in- and outpatient facilities for children and adolescents between 0 and 23 years of age, with a psychiatric disorder and a (mild) intellectual disability ([M]ID). Children with (M)ID have an increased risk of developing psychiatric problems. Given the negative short- and long term effects of mental illness on young people and their families, effective treatment is essential. To reach effective treatment, children and families have to overcome some stressful situations by getting to the health care services. Sensory overload can occur while travelling and waiting in crowded environment, with negative effect on wellbeing and treatment. Studies that review barriers and facilitators to enable healthcare service stated that healthcare settings should seek to minimise sensory sensitivities where possible.

Methods We will discuss the experiences of different treatments given in the Van to children and parents

Aims/Results During this symposium we give you a digital view of the Van "GIJS." Do you dare to get in and experience the possibilities of different treatments?

Conclusion Several treatments are possible. Consider for example: Trauma treatment (EMDR), play therapy, cognitive behavioural therapy or psychoeducation.

From Science to Practise In order to achieve a practical solution for the scientific statement of minimizing sensory sensitivities and to introduce accessible care for families, we developed a mobile consultation room in a sustainable electric Van. We drive our Van to home situations, day care facilities, schools and institutions. We receive positive response from families and colleagues, about the positive impact on their wellbeing, self confidence, mood, trauma and function

Treatment at your doorstep : Innovative Healthcare with "The Banjaard Bus "

1CLM van Vliet, 2KC Dekker, 3EMN van Ooijen, 4E Planque

1,2,3,4 Youz, de Banjaard/Parnassiagroep

Keywords Children, Innovative Care, Psychiatric treatment

Background The Banjaard is a multi-disciplinary clinic with in- and outpatient facilities for children and adolescents between 0 and 23 years of age, with a psychiatric disorder and a (mild) intellectual disability ([M]ID. Children with (M)ID have an increased risk of developing psychiatric problems. Given the negative short- and long term effects of mental illness on young people and their families, effective treatment is essential. To reach effective treatment, children and families have to overcome some stressful situations by getting to the health care services. Sensory overload can occur while travelling and waiting in crowded environment, with negative effect on wellbeing and treatment. Studies that review barriers and facilitators to enable healthcare service stated that healthcare settings should seek to minimise sensory sensitivities where possible.

Methods We are currently conducting a pilot study into the effectiveness, feasibility and client satisfaction following treatment in the Banjaard Bus

Aims/Results In an interactive symposium, we will describe and demonstrate our innovative project developed for children with intellectual disabilities and their families.

Conclusion The Banjaard makes psychiatric treatment accessible to children in their immediate living environment with an attractive mobile treatment Van

From Science to Practise In order to achieve a practical solution for the scientific statement of minimalizing sensory sensitivities and to introduce accessible care for families, we developed a mobile consultation room in a sustainable electric Van. We drive our Van to home situations, day care facilities, schools and institutions. We receive positive response from families and colleagues, about the positive impact on their wellbeing, self-confidence, mood, trauma and function

Treatment at your doorstep : Different treatments in a safe and homely atmosphere setting

2KC Dekker,

2Youz/de Banjaard Parnassiagroep

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their families, effective treatment is essential. To reach effective treatment, children and families have to overcome some stressful situations by getting to the health care services. Sensory overload can occur while travelling and waiting in crowded environment, with negative effect on wellbeing and treatment. Studies that review barriers and facilitators to enable healthcare service stated that healthcare settings should seek to minimise sensory sensitivities where possible.

Methods We will discuss the experiences of different treatments given in the Van to children and parents

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Treatment at your doorstep : "Playing and Recovering on Wheels"

3EMN van Ooijen,

4E. Planqué, Youz/De Banjaard Parnassiagroep

Keywords Children, Innovative Care, Psychiatric treatment

Background The Banjaard is a multi-disciplinary clinic with in- and outpatient facilities for children and adolescents between 0 and 23 years of age, with a psychiatric disorder and a (mild) intellectual disability ([M]ID. Children with (M)ID have an increased risk of developing psychiatric problems. Given the negative short- and long term effects of mental illness on young people and their families, effective treatment is essential. To reach effective treatment, children and families have to overcome some stressful situations by getting to the health care services. Sensory overload can occur while travelling and waiting in crowded environment, with negative effect on wellbeing and treatment. Studies that review barriers and facilitators to enable healthcare service stated that healthcare settings should seek to minimise sensory sensitivities where possible.

Methods Infant Mental Health treatment in a Van

Aims/Results By using video material we would give you an impression how we work with these young children, providing Pivotal Response Treatment (PRT), Storytelling and Theraplay

Conclusion The Van is a good treatment facility, especially for the very young and their families and child-day care teacher to give treatment without stress

From Science to Practise In order to achieve a practical solution for the scientific statement of minimalizing sensory sensitivities and to introduce accessible care for families, we developed a mobile consultation room in a sustainable electric Van. We drive our Van to home situations, day care facilities, schools and institutions. We receive positive response from families and colleagues, about the positive impact on their wellbeing, self-confidence, mood, trauma and function

Treatment at your doorstep : “GIJS: From idea to reality”

1CLM van Vliet,

Youz/de Banjaard Parnassiagroep

Keywords Children, Innovative Care, Psychiatric treatment

Background The Banjaard is a multi-disciplinary clinic with in- and outpatient facilities for children and adolescents between 0 and 23 years of age, with a psychiatric disorder and a (mild) intellectual disability ([M]ID. Children with (M)ID have an increased risk of developing psychiatric problems. Given the negative short- and long term effects of mental illness on young people and their families, effective treatment is essential. To reach effective treatment, children and families have to overcome some stressful situations by getting to the health care services. Sensory overload can occur while travelling and waiting in crowded environment, with negative effect on wellbeing and treatment. Studies that review barriers and facilitators to enable healthcare service stated that healthcare settings should seek to minimise sensory sensitivities where possible.

Methods Introduction of the project to start “treatment at the doorstep”; mobile accessible care possible at any place to make treatment as easy as possible for our patients and healthcare colleagues.

Aims/Results In this presentation we show you “Why we initiated this innovation” and “how we set up the project” first project results. We also present the process of realization of "the Banjaard Bus" in a short film.

Conclusion The innovative project has a positive impact on wellbeing of families and stress reduction

From Science to Practise In order to achieve a practical solution for the scientific statement of minimalizing sensory sensitivities and to introduce accessible care for families, we developed a mobile consultation room in a sustainable electric Van. We drive our Van to home situations, day care facilities, schools and institutions. We receive positive response from families and colleagues, about the positive impact on their wellbeing, self confidence, mood, trauma and function

Symposia two (SoS-2 E/OS)

Topic: Challenging Behaviour

ADHD in people with Intellectual Disabilities- Challenges and dilemmas

1Bhathika Perera, 1 Ken Courtenay, 2 Evan Yacoub

1 Barnet, Enfield and Haringey Mental Health Trust, London, UK, 2 Brothers of Charity Services, Galway, Ireland,

Keywords ADHD, Intellectual Disability, Stimulants, Hyperkinetic disorder

This symposium covers three subject areas.

ADHD in intellectual disability: Findings from a national audit (B. Perera)The audit is the biggest study undertaken on ADHD in 445 adults with intellectual disability. The findings revealed significantly high prevalence rates of comorbid mental illnesses, challenging behaviour, and neurodevelopmental disorders. People with ADHD and intellectual disability not prescribed ADHD medications were using more antipsychotic medications compared to people taking ADHD medications. In the presentation, the findings of the audit are presented and their applicability in clinical practice is explored.

ADHD in intellectual disability: Royal College of Psychiatrists report UK (Ken Courtenay)

National and international guidelines on ADHD focus on the care ADHD in people without intellectual disability. A lack of guidelines on ADHD in intellectual disability has limited the diagnosis and treatment/management of people with the disorder. The presentation highlights the importance of developing clear guidelines for clinical practice.

Defining functional impairment in people with ADHD and intellectual disability (Evan Yacoub)

The presence of functional impairment is a major criterion in the diagnosis of ADHD.

Functional impairment can manifest in employment, relationships, emotional wellbeing and other domains in people without intellectual disability. Defining functional impairment can be challenging in people with intellectual disability. The presentation considers the current evidence base on defining functional

impairment in people with ADHD and intellectual disability, the current assessment tools, and the areas of functional impairment often forgotten in people with intellectual disability and ADHD.

From Science to Practise This symposium highlights how the findings on diagnosis and treatment of ADHD and intellectual disability are applicable in clinical practice.

Defining Functional Impairment in People with ADHD and intellectual disability **Evan Yacoub**

Brothers of Charity Services, Galway, Ireland

Keywords ADHD, Intellectual Disability, Hyperkinetic disorder, functional impairment, challenging behaviour

Background Functional impairment is one of the essential criteria to diagnose ADHD. It can be manifested in different domains such as family, employment, academic, relationships, emotional wellbeing, criminality and substance misuse.

Methods Defining functional impairment in people with ADHD and intellectual disability can be difficult as life experiences and opportunities are limited in people with intellectual disability compared to their peers without intellectual disability. Functional impairment can often be limited to challenging behaviour.

Aims We aim to discuss the importance of defining functional impairment in people with ADHD and intellectual disability. Secondly, we aim to discuss hidden functional impairments that are difficult to assess and quantify.

Results Rating scales looking at challenging behaviour and other emotional difficulties such as anxiety can be used to quantify functional impairment caused by ADHD. A clear formulation of the person's presentation and its association with ADHD symptoms helps to make links to functional impairment.

Conclusions It is difficult to assess functional impairment in people with intellectual disability using standard rating scales used in the general population. Functional impairment observed in people with intellectual disability is often due to hyperactivity and impulsivity. It can be challenging to define the functional impairment due to inattention caused by ADHD in people with intellectual disability.

From Science to Practise Careful consideration should be given to assess functional impairment in people with ADHD and intellectual disability. This can be used as a marker of response to treatment.

Disclosures 1 Bhatika Perera - Honoraria from Flynn Pharma

ADHD in intellectual disability: Royal College of Psychiatrists Report UK

Ken Courtenay

Barnet, Enfield and Haringey Mental Health Trust, North London, UK

Keywords ADHD, Intellectual disability, challenging behaviour

Background Diagnosis of ADHD in people with intellectual disabilities can often be challenging due to multiple factors. Symptoms of ADHD can also be related to intellectual disability. Furthermore, significant comorbidities such as ASD and mental illnesses can make the diagnostic process challenging. This often leads to underdiagnosis. Similarly, treatment of ADHD in people with intellectual disability needs to be carefully planned. There are no national guidelines on the diagnosis and treatment of ADHD in people with intellectual disability.

Methods ADHD in intellectual disability special interest group of the Royal College of Psychiatrists in the UK developed guidelines on the diagnosis and treatment of ADHD in people with intellectual disability.

Results/Aims College report on ADHD in intellectual disability discuss the diagnostic process, challenges to making the diagnosis and how to overcome those challenges. It also looks at psychiatric comorbidities in people with ADHD and intellectual disability. It analyses the evidence base on pharmacological and non-pharmacological treatment for ADHD in people with intellectual disability and provides guidelines on treatment.

Conclusions Diagnosis and treatment of ADHD can improve the quality of life of people with intellectual disability. Further research is needed to improve the evidence base for supporting people with ADHD and intellectual disability.

From Science to Practise RCPsych College report on ADHD in intellectual disability provides step by step guidance on diagnosis and treatment of ADHD in intellectual disability. It also helps clinicians to understand the challenges with diagnosis and treatment.

ADHD in intellectual disability: Findings from the UK National Audit

Bhathika Perera

Barnet, Enfield and Haringey Mental Health Trust, North London, UK

Background ADHD in people with intellectual disabilities is often under-recognised despite a high prevalence rate and evidence-based interventions. Research into ADHD in intellectual disability is also very limited. This audit identifies and analyses real-world characteristics, diagnostic practices, treatment, and management of ADHD in adults with intellectual disability.

Methods Pooled retrospective case note data for people with intellectual disability and ADHD, collected from 30 organizations across the UK, were

analysed. Patients were classified into mild and moderate-profound intellectual disability groups. Associated mental health and neurodevelopmental co-morbidity, Demographics, concomitant psychotropics, and mental and behavioural concerns were collected. Group differences were reported using logistic regression models.

Results/Aims Of 445 participants, 73% had co-occurring autism spectrum disorder (ASD) and 65% were prescribed ADHD medications. Those on ADHD medication were less likely to be prescribed antipsychotics ($p < 0.001$) and antidepressants ($p < 0.001$). Multiple significant differences were found in ADHD medication response between intellectual disability groups and those with/without co-morbid ASD but not associated with challenging behaviour reduction.

Conclusions High levels of neurodevelopmental and psychiatric comorbidity were found. Intellectual disability severity and the presence of ASD appear to influence the use of certain psychotropic medications. Appropriate use of ADHD medication appears to reduce psychotropic polypharmacy.

From Science to Practise This study raises the complexity of people with intellectual disability and ADHD due to significant comorbidities. It further raises the possibility that the use of ADHD medications may reduce the use of antipsychotic medications in people with intellectual disability.

Symposia three (SoS-3 E/OS)

Topic: Mental Disorders

Patients with intellectual disabilities in specialist mental health services in Singapore

Jonathan Ee (1, 2)

(1) University of Birmingham, The Centre for Applied Psychology, UK (2)

Institute of Mental

Health, Singapore

Keywords: intellectual disability, specialist mental health services, service users, family carers, mental health professionals

Background: People with intellectual disabilities have a higher vulnerability of developing mental health problems, however they have poorer accessibility to mental health services. A specialist mental health service for adult persons with intellectual disabilities was started in Singapore to better cater for the needs in this population.

Methods: This research explores the experiences of different stakeholders (mental health professionals, family carers and service users) regarding the

provision of specialist mental health services for people with intellectual disabilities in Singapore.

Results: Mental health professionals shared about their lack of skills and knowledge, as well as feelings of uncertainty and fear when working with this population. Issues pertaining to inpatient care of people with intellectual disabilities were discussed among the different stakeholders. Family carers found it challenging to manage the mental health problems of their relatives in the community and often relied on mental health professionals' support and advice during the treatment process. Service users found that their choice and autonomy were restricted during inpatient admission and yearned to be part of their community through work and having social relationships.

Conclusions: These findings provide an increased understanding of the lived experiences of different stakeholders and the impact of the culture of Singapore on the provision of mental health services and outcomes of people with intellectual disabilities.

From Science to practice: Recommendations are made for service delivery, improving clinical practice and staff competency.

Improving mental health for individuals with developmental disabilities: Results from clinical research.

Trine Lise Bakken (1), Heidi Sageng Sommerstad (2), Jonathan Ee (4, 5), Thomas Bergmann (3)

(1) National Advisory Unit on Mental Health and Intellectual Disability / Oslo University Hospital, Norway. (2) Regional department for Mental Health in Intellectual Disability / Oslo university, Norway. (3) Center for Mental Health in Developmental Disabilities, Ev. Krankenhaus Königin Elisabeth Herzberge, Berlin, Germany. (4) University of Birmingham, The Centre for Applied Psychology, UK (5) Institute of Mental Health, Singapore

Keywords: intellectual disability, mental health, clinical research, user involvement,

Background: There is a dearth of empirical research on clinical practice related to mental health in intellectual disabilities. Likewise, the patient's voice in empirical research is inconspicuous.

Methods: Four articles are included. All include methods involving clinical practice. The first paper investigates the use of behavioural equivalents to conventional criteria in assessment of schizophrenia in patients with autism and intellectual disabilities. The second paper is investigating the experiences from patients in a specialized psychiatric inpatient unit. The third paper presents clinical services for patients with intellectual disabilities and co-morbid

mental ill health. The last paper presents psycho-education for patients with autism and intellectual disabilities.

Results: The four papers present different aspects of improvements in clinical practice encompassing diagnostic assessment (Bakken), mental health nursing (Sommerstad), psycho-education (Bergmann), and services (Ee).

Conclusions: The results from the four articles confirm previous research emphasizing that patients with intellectual disabilities profit from the same core elements in clinical practice found for the general population, when adjusted to cognitive and emotional challenges.

From Science to Practice: Clinical studies are important for patients with intellectual disabilities and mental health issues. The patients' experiences underpin the importance of user involvement in clinical research.

Experiences of ward atmosphere in inpatients with intellectual disability and mental illness

Heidi Sageng Sommerstad (1), Trine Lise Bakken (2)

(1) Regional department for Mental Health in Intellectual Disability / Oslo university, Norway, (2) National Advisory Unit on Mental Health and Intellectual Disability / Oslo University Hospital, Norway.

Keywords: intellectual disability, patient experiences, mental health, inpatient treatment, mental health nursing

Background: Patients with intellectual disability in psychiatric services are rarely asked about their experiences when admitted to inpatient units. The aim was to enhance the understanding of ward atmosphere for inpatients with co-occurring intellectual disability and mental illness by exploring patients' experiences from a specialised mental health inpatient unit.

Methods: A selected sample of ten adults with comorbid mental illness and intellectual disability were recruited for a qualitative interview study based on Gunderson's conceptualisation of therapeutic components in mental health wards. The patients were interviewed by two experienced clinicians and interviews were analysed using directed content analysis.

Results: Patients' experience of their relationships with ward staff seemed central to their experiences of several aspects of mental health nursing. Feeling safe, contained, and validated, were further important aspects. However, the patients seemed to have little influence on treatment choices and did not report participating in shared decision-making.

Conclusions: The patients' answers in this study are in line with previous research on ward atmosphere for patients in the general population.

Relations between patients and therapists are the core element for patient satisfaction.

From Science to Practice: Patient experiences are vital to inform future mental health nursing for patients with intellectual disability, both in inpatient and ambulatory services.

Evaluation of a multimodal Group Training supporting People with Autism and Intellectual Disability

Thomas Bergmann (1)

(1) Center for Mental Health in Developmental Disabilities, Ev. Krankenhaus Königin

Elisabeth Herzberge, Berlin, Germany

Keywords: autism spectrum disorder, intellectual disability, emotional regulation, social skills, psycho-education

Background: Autism spectrum disorders (ASD) are often associated with intellectual disability, and mental health issues. ASD-specific group concepts usually focus on people on a high functioning level. The Autism-Competence-Group (AutCom) combines a psycho-educative approach with music and dance/movement interventions in adults with ASD and intellectual disability. AutCom includes 16 structured sessions of 90 minutes to foster social and emotional competencies. This study investigates the appropriateness and effectiveness of AutCom.

Methods: Practicability and appropriateness were measured based on participation frequency and patient satisfaction (CSQ-8). Efficacy was assessed in a pre-post design (N=12) based on self- and third-party assessment with a control group matched by gender and level of intellectual disability. Primary outcome variables were social and emotional competence, and secondary outcomes were challenging behaviour and quality of life.

Results: A participation rate of 86% indicated practicability; high CSQ-8 scores (M=30 of max. 32) indicated appropriateness. Significant improvement was found in social competence compared to the control group and emotional competence in the pre-post self-assessment on the AutCom questionnaire. No significant improvement was found in challenging behaviour and quality of life.

Conclusion: AutCom is shown to be a promising and highly accepted group concept in fostering social and emotional skills in adults with ASD and intellectual disability.

From Science to Practice: AutCom has the potential for positive impact on mental wellbeing for individual with ASD and intellectual disability.

Behavioural equivalents of schizophrenia in patients with intellectual disability and autism

Trine Lise Bakken (1)

(1) National Advisory Unit on Mental Health and Intellectual Disability / Oslo University Hospital, Norway

Keywords: autism, intellectual disability, schizophrenia, diagnostic assessment, behavioural equivalents

Background: Assessment of schizophrenia (SCZ) in people with autism spectrum disorder (ASD) is complicated due to confounding symptoms between ASD and SCZ. These confounding factors are aggravated when the patient has sparse verbal skills.

Methods: A selective review was conducted to identify behavioural equivalents when assessing SCZ in individuals with ASD with sparse verbal skills, from 16 years of age. Only clinical papers were reviewed. Eight relevant articles were analysed for the use of behavioural equivalents in clinical settings.

Results: The results showed that especially disorganized speech and behaviour and negative symptoms can be observed in patients with SCZ and ASD who speak sparsely. It is not possible to observe delusions, but they may be reported by the patients when treated adequately for some time, usually months. Hallucinations cannot be observed directly, but “hallucinatory behaviour” may be interpreted as hallucinations when observed concurrently with other SCZ symptoms. Additionally, age of onset and marked impaired global functioning compared to habitual functioning may constitute a diagnosis of SCZ in ASD. ASD is considered a lifelong condition and may be identified within the first 3 – 4 years, while SCZ onset is usually in adolescence or early adulthood.

Conclusions: Four out of five core symptoms of schizophrenia were described as observable, and hence may be used as equivalents to conventional criteria of schizophrenia.

From Science to practice: The use of behavioural equivalents may improve the assessment of schizophrenia in individuals with ASD and intellectual disability.

[Symposia four \(SoS-4 E/OS\)](#)

[Topic: Models of Care and Support](#)

The art therapy interventions for an individual with Down Syndrome

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1 Croatian Art Therapy Association HART, Zagreb, Croatia

Keywords art therapy, Down Syndrome, intellectual disability, developmental disability, PPAT

Background Most persons with Down Syndrome (DS) have intellectual developmental disabilities and specific deficits in short-term memory for verbal information. However, their ability to learn from visual information is their strength and art therapy opens up as an ideal medium for working with individuals with DS.

Methods This case report shows a 32 year old individual with DS and moderate intellectual disability that didn't want to move from family house to the new neighbourhood and new flat. He was guided in weekly individual art therapy sessions that lasted sixty minutes using the Expressive Therapies Continuum (ETC) as a framework for interventions. The Person Picking an Apple from a Tree (PPAT) was used to examine the progress of art therapy interventions over the period of eight months.

Results/Aims There was improvement in 13 PPAT subscales (prominence of colour, colour fit, implied energy, space, integration, logic, realism, problem-solving, developmental level, details of objects and environment, line quality, person, rotation). The only scale that stayed the same was perseveration.

Conclusions Art therapy interventions showed to be effective in the individual with DS to help him process emotions through a stressful period and traumatic situation torn out of his accustomed environment. This transition ended with positive results for him and his family moving peacefully and happy.

From Science to Practise Art therapy interventions are promising to support individuals with DS to process their emotions, reduce stress and may contribute to improve the quality of life.

Music therapy interventions for affect regulation in adults with severe multiple disabilities

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1 St. Elisabeth-Haus Lichtenrade; University of the Arts, Berlin, Germany

Keywords music therapy, severe multiple disabilities, developmental psychology, affect regulation, psychomotor arousal

Background Adults with severe multiple disabilities show a high prevalence of stress and strain characters, including motor tension, stereotyped behaviours, self-stimulation and self-injury. Music interventions such as lullabies are worldwide used in calming down babies and music therapy has a great potential to regulate psychomotor arousal. The aim of this study is to explore

developmentally oriented music therapy interventions for affect regulation in adults with severe multiple disabilities.

Methods Music therapy sessions with 12 adults with severe multiple disabilities have been examined micro-analytically with the Assessment of the Quality of Relationship (AQR) The AQR measures the matching of music interventions with the client's level of emotional development as indicator for meeting the client's needs. The frequency and quality of stress and strain characters were specially focused. Music therapy interventions in sequences with no signs of stress were examined in particular.

Results/Aims Signs of stress decreased or even did not appear when the therapist intervened according to the level of emotional development and the current needs of the clients. Especially attuning the music to the emotional state of the persons and letting them feel the vibrations of musical instruments led to calmness and attention.

Conclusions Music therapy interventions based on the level of emotional development may help to regulate psychomotor arousal in people with severe multiple disabilities.

From Science to Practise Assessing the physical and emotional expression of adults with severe multiple disabilities is crucial to meet their needs. Music-based interventions might contribute to a regulated affective state and build the base for attention, exploratory behaviour and thus further development.

Improvisational drama therapy for people with intellectual disabilities and mental health problems

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1,2,3,4 Center for Mental Health in Developmental Disabilities, Ev.
Krankenhaus Königin Elisabeth Herzberge, Berlin, Germany

Keywords drama therapy, improvisational theatre, intellectual disabilities, mental disorders

Background Mental disorders are prevalent in persons with intellectual disabilities and experience- based interventions are appropriate to address their needs. Drama therapy is a promising complementary approach, recent studies found an impact on creativity and psychological well-being using interventions based on improvisational theatre (improv). However, little research addresses its application in persons with intellectual disabilities and mental health problems. This study examines feasibility and appropriateness of improv interventions in this population.

Methods Over a period of five years, a manualized treatment model based on improv was implemented in two groups differing in the participants' intellectual and socio-emotional abilities. The sessions lasted 75 minutes and were conducted every two weeks by a family therapist qualified in improv. The feasibility of the intervention was measured by the average participation period of all participants (N = 24). A subsample (n = 12) took part in assessing appropriateness through qualitative measurements from the perspective of the participants, two independent observers and the therapist.

Results/Aims The average participation period was 19 months. The qualitative assessments suggested that the applied drama therapy treatment model was well-received and appropriate. Of all drama therapy methods applied, improv methods were reported as most appealing.

Conclusions Improvisational drama therapy proved to be feasible and appropriate in persons with intellectual disabilities and mental disorders. The participants' cognitive and socioemotional abilities should be considered when planning and implementing the intervention. Future research should consider the intervention's effectiveness and efficacy.

From Science to Practise Drama therapy based on improvisational theatre is highly accepted amongst people with intellectual disabilities and mental health problems and may improve psychological well-being in this group.

From practice to research. Arts-based interventions in adults with intellectual disabilities.

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Keywords arts therapy, intellectual disability, adults, music, dance, drama,

Background Creative Arts Therapies (CAT) is an umbrella term for healthcare professions using the creative and expressive process of music, dance/movement, drama, and art-making to improve psychological and social well-being. Interventions and settings are manifold and CATs are widely used for people on a lower level of functioning due to their non-verbal, bodily, and experience-based character. However, systematic research in CATs for people with intellectual disability is rare.

Methods In four studies a broad range of arts-based interventions and settings will be presented systematically applied in adults with different degrees of impairment. CAT-specific assessments were applied to measure progress and quality of interventions. An improvisational drama therapy group

intervention and a musical-bodily group training (AutCom) for people on the autism spectrum were evaluated on appropriateness.

Results/Aims In all studies arts-based concepts and systematically applied interventions showed to be appropriate and well accepted by the clients. Developmentally oriented music therapy interventions had high potential to regulate psychomotor arousal in multiple disabled persons, art-making supported an individual with Down Syndrome to master a stressful transitional life-event, improvisational drama therapy was highly feasible when recognizing cognitive and socio-emotional abilities, and AutCom showed to be promising in combining arts-based interventions with education.

Conclusions CAT-interventions systematically applied by trained professionals showed to be supportive and well accepted across different settings and levels of intellectual disabilities.

From Science to Practise Art, dance, music, and drama interventions are widely used in therapy and education of people with intellectual disabilities, their potential should be further evaluated systematically.

AutCom: Musical-bodily interventions in supporting adults with intellectual disability and autism

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Keywords autism spectrum disorder, intellectual disability, adults, group training, music therapy

Background Amongst people with intellectual disability those with an additional autism spectrum disorder (ASD) are a highly vulnerable group. ASD group trainings are provided for adolescents and adults on a higher level of functioning, however, intellectual disability-specific concepts are rare. This study asks for a suitable framework and appropriate interventions to support adults with intellectual disability and ASD.

Methods In a specialized outpatient clinic for adults with intellectual disability the Autism Competency Group (AutCom) has been developed by a music therapist, a pedagogue and a psychologist. Treatment goals were identified through structured interviews with six participants before the 9-month training. An ASD-friendly framework and interventions combining an embodied arts-based approach with educational principals have been developed based on literature and interdisciplinary clinical experience. Acceptance was

measured by patient satisfaction questionnaire und final semi-structured interviews with the participants.

Results/Aims Emotion recognition and stress regulation were the participant's primary treatment goals. Following the TEACCH approach spatial and temporal structure with visual aids (e.g., icons, comic strip conversations) were implemented. Interventions were based on mindfulness, musical dynamics and interaction, roleplay combined with education, and dance and motion exercises with focus on interpersonal synchrony. CSQ-8 scores were extremely high (M=30 of max. 32), participant's feedback highlighted the music and dance activities, fun in being social, and learning outcomes in stress regulation.

Conclusions Musical-bodily interventions were highly accepted by the participants and may have potential in fostering stress regulation and social skills.

From Science to Practise AutCom is a promising approach to support adults with intellectual disability and ASD combining arts-based and educational interventions.

Symposia five (SoS-5 E/OS)

Topic: Autism Spectrum Disorder an Related Developmental Disorders

Validation of the German version of the PDD-MRS in an adult sample with intellectual disability and suspect of ASD

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Keywords autism spectrum disorder, intellectual disability, adults, diagnostics, screening

Background The Scale for Pervasive Developmental Disorders in Mentally Retarded Persons (PDD-MRS) is a scale specifically developed for persons with an intellectual disability to screen for autism spectrum disorders (ASD). In the Dutch normative sample (N=1230), sensitivity and specificity showed to be 92.4%, respectively. In this study, the diagnostic validity of the German version of the PDD-MRS was assessed.

Methods In a clinical sample of adults with intellectual disability and mental ill-health suspected of comorbid ASD (N= 109), the PDD-MRS was applied. The diagnostic validity was assessed and the correlation with common screeners was evaluated.

Results/Aims Based on the cut-off score of 10, sensitivity was 89%, specificity was 62%, and the Area Under the Curve (AUC) was .83. Sensitivity/specificity in persons with mild to moderate intellectual disability showed better criterion validity (85%/73%) compared to those with severe to profound intellectual disability (93%/42%). The PDD-MRS score correlated significantly with convergent ASD screening measures ($r = .3$ to $.6$).

Conclusions The German version of the PDD-MRS showed good sensitivity but limited specificity values compared to previous studies. This may be due to the high symptom load in this clinical sample.

From Science to Practise The PDD-MRS is a valid screening measure for diagnosing ASD in adults with intellectual disability, especially in those with mild to moderate intellectual disability.

Disclosures 4 Tanja Sappok receives royalties from Hogrefe Publishing

Validation of the DiBAS-R in an independent sample of adults with intellectual disability

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Keywords autism spectrum disorder, intellectual disability, adults, diagnosis, screening

Background Diagnosing autism spectrum disorders (ASD) in adults with an intellectual disability is time consuming and challenging. However, the correct diagnostic assignment is pivotal for appropriate treatment and support. This study aims to evaluate the diagnostic validity of the Diagnostic Behavioral Assessment for Autism Spectrum Disorders-Revised (DiBAS-R), a screening instrument for ASD in adults with intellectual disability.

Methods The DiBAS-R was applied in 381 adults with intellectual disability and suspect of ASD. Psychometric properties were tested against the diagnostic decision of a were compared to the diagnosis of a multidisciplinary consensus conference in this independent sample.

Results/Aims In the overall sample, the DiBAS-R showed a sensitivity of .82 and a specificity of .67. While in mild to moderate intellectual disability overall agreement (.83) sensitivity (.79) and specificity (.84) were acceptable, the results were less balanced in severe to profound intellectual disability (sensitivity: .83, specificity: .34, overall agreement: .51).

Conclusions The DiBAS-R is a valuable screening instrument to detect ASD in adults with intellectual disability, specifically in mild to moderate intellectual disability.

From Science to Practise ASD-screening can be applied in adults with intellectual disability. The diagnosis of an ASD can help to explain challenging behaviour in adults with intellectual disability allowing for appropriate treatment and support.

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Towards a diagnostic standard in detecting autism spectrum disorders in adults with intellectual disability

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Keywords autism spectrum disorder, intellectual disability, adults, diagnostics, screening

Background Every fifth person with an intellectual disability has an additional autism spectrum disorder (ASD) which remains often undetected until adulthood. The combination of intellectual disability and ASD is often associated with severe challenging behaviours. In light of the diagnostic challenge due to the symptom overlap of intellectual disability and ASD, there is a need for intellectual disability-specific diagnostic instruments. We want to reflect on a possible diagnostic standard for the German-speaking area and discuss intellectual disability-specific ASD diagnostics on an international level.

Methods Replications of the psychometric properties of the following intellectual disability-specific measures will be presented: the Diagnostic Behavioral Assessment for ASD-Revised (DiBAS-R), an economic ASD screener; the German version of the Scale for Pervasive Developmental Disorders in Mentally Retarded Persons (PDD-MRS), a structured interview with reference persons; and the Music-based Scale for Autism Diagnostics (MUSAD), a comprehensive observational instrument. Finally, these intellectual disability-specific scales have been correlated and compared with expert diagnoses in a German clinical sample (N=108).

Results/Aims The replication studies of all three scales supported their clinical utility. Low to moderate correlations between the scale scores and a broad range of agreement with diagnostic assignment indicated that a combination of measures should be used for a comprehensive assessment.

Conclusions The DiBAS-R, the PDD-MRS, and the MUSAD are psychometrically sound instruments for ASD-screening and comprehensive diagnostics in adults with intellectual disability.

From Science to Practise Different intellectual disability-specific scales are available to support ASD-diagnostics.

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The convergent validity of ASD measures in adults with intellectual disabilities

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Keywords autism spectrum disorder, intellectual disability, adults, diagnostics, screening

Background Meanwhile, an increasing number of diagnostic measures for people with intellectual disability and suspect of autism spectrum disorders (ASD) is available. Instruments such as the Scale for Pervasive Developmental Disorders in Mentally Retarded Persons (PDD-MRS), the Diagnostic Behavioral Assessment for ASD (DiBAS-R), or the Music-based Scale for Autism Diagnostics (MUSAD) have proven psychometric soundness. However, little is known about the measures convergence.

Methods We analysed data from N = 108 adults with intellectual disability assessed with intellectual disabilities-specific (e.g., PDD-MRS, DiBAS-R, MUSAD) and intellectual disability-nonspecific (e.g., the Social-Communication Questionnaire, SCQ) ASD diagnostic tools. We assessed the scales' convergent validity in terms of (1) correlations between the scales' scores and (2) pairwise agreement between the scales in their diagnostic assignment. We also determined the agreement of each scale with the clinical diagnosis.

Results/Aims The correlations between the ASD severity scores ranged from .28 to .51. Pairwise agreement between scales ranged from 56% to 71%, with kappa values ranging from .13 to .38. Agreement with the clinical diagnosis ranged from 55% to 78%, with sensitivity/specificity values ranging from .51 to .78 and .61 to .82, respectively.

Conclusions The low to moderate correlations between the severity scores and the range of agreements in diagnostic assignment indicate that all scales provide non-interchangeable and complementary perspectives on an individual's spectrum of ASD-related symptoms.

From Science to Practise The usage of several intellectual disability-specific scales is recommended when diagnosing ASD in adults with intellectual disability. Research on optimal combinations of screening tools is desirable.

Disclosures 1,2,3 All authors receive royalties from Hogrefe Publishing

Replication of the diagnostic validity of the Music-based Scale for Autism Diagnostics (MUSAD)

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Keywords autism spectrum disorder, intellectual disability, diagnostics, observational measure, music

Background The MUSAD is a structured, DSM-5-based observational measure that creates nonverbal situations of musical interaction in which ASD symptomatology can be assessed. In 2019, a diagnostic algorithm has been developed in a clinical sample (N = 124; sensitivity = .79, specificity = .74, AUC = .81, interrater reliability .92). The present study aims to replicate these findings in a second, independent sample.

Methods The MUSAD was applied to 71 adults with intellectual disability representing all levels of impairment. MUSAD scores were compared to the judgments of an expert consensus conference based on established measures. In addition, the assessments of two independent raters were compared to determine interrater reliability (IRR) for a subsample (n = 10) using intra-class correlation (ICC).

Results/Aims In 62 (87.3%) persons, the MUSAD assigned participants to the same diagnostic group as the consensus conference (sensitivity = .87, 95% CI [0.77; 0.96], specificity = .89, 95% CI [0.74; 1.0], AUC = .90, 95% CI [0.81; 0.97]). Interrater reliability was 0.88, 95% CI [0.61; 0.97].

Conclusions The present study replicates initial evidence on the MUSAD's ASD diagnostic validity and objectivity with similarly promising coefficients in an independent sample of adults with intellectual disability.

From Science to Practise This study supports the MUSAD's diagnostic utility by replicating previous findings. Thus, the MUSAD is an appropriate instrument for diagnosing ASD in people with intellectual disability.

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Symposia six (SoS-6 E/OS)

Topic: Models of Care and Support

The pros and cons of the integrative framework: New authority and emotional development

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12Multiversum

Keywords the new authority, emotional development, psychiatric hospital

Background In Multiversum, a psychiatric hospital in Antwerp, Belgium we treat people aged 16 years and older with an intellectual disability and mental health problems or a behavioural disorder. We offer residential, semi-residential, ambulant and outreach treatment. By integrating two different models, we try to optimize the relation between caregivers and patients.

Methods We have investigated the impact of the integrative framework from different perspectives: the patient, the caregiver, the relationship between the two, the context, the impact on coercive measures, ...

Results/Aims We expect that the treatment of the patients with severe mental problems and an intellectual disability will be better (more quality).

Conclusions The use of the integrative framework gives us a lot of pros: better communication skills and less helplessness for the staff. Less escalation and less acting out from the patients, ... Some cons: very intensive for the staff, mind switch necessary, ...

From Science to Practise By using and integrating these two models we aim to offer our patients a treatment environment that is adjusted to their emotional level and with avoidance of violence. Simultaneously with working together with the patient's familiar network to regain strength in their normal daily life.

Integrating the New Authority and Emotional Development Model in Practice

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Keywords new authority, emotional development, psychiatric hospital

Background In July 2019, a seventeen year old girl was admitted to our closed ward in Multiversum psychiatric hospital in Antwerp, Belgium. The patient had been diagnosed with autism spectrum disorder, mild intellectual disability, a major depressive disorder and behavioural problems. She had been treated with lithium and fluoxetine. Quetiapine was paused because of weight gain. In the first few months of her stay in our hospital, the depressive symptoms worsened, resulting in increasing amounts of suicide attempts. In reaction, we

installed restricted measurements and a protective attitude. Suicide attempts and self-harming behaviour occurred on a weekly basis.

Methods During the treatment in the children's hospital, the patient was scaled in a phase 2 of emotional development level. Because of this result our daily approach was mainly being present. In addition to the concept of new authority (NA) was introduced in the patient's treatment after 1 year of hospitalization: 'more distant presence' with additional responsibility for the patient, but with continuous availability of the staff.

Results/Aims After integrating NA we noticed a decrease in self-destructive behaviour and suicide attempts. Because of this the staff was able to increase their own strength in their daily work. We took into account that the patient could feel rejected, luckily this was not the case, moreover she herself was proud of the changes in her behaviour.

Conclusions The combination of integrating both models in the treatment resulted in a positive evolution in behaviour & emotional well-being of the patient and an increasing feeling of strength for staff.

From Science to Practise We organize internal trainings and peer-to-peer coaching. In this way we can assess the practice to the science.

Complex case ask for caregiver. Haim Omer and Anton Dösen give the answer.

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5Hoefnagels Goedele,

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Keywords the new authority, emotional development, psychiatric hospital

Background In Multiversum, a psychiatric hospital in Belgium we treat people adults with an intellectual disability and mental health problems . We offer residential, ambulant and outreach treatment. By integrating two different models, we try to optimize the relation between caregivers and patients.

Methods The concept of the new authority, founded by Haim Omer, designates a positive and legitimate kind of authority, which contrasts with the 'old' authority. The new authority however is based on presence, self-control and a network of support in order to cope with violent and self-destructive behaviour by children and adolescents.

Anton Dösen's concept of emotional development states that individuals at a certain stage of development show specific adaptive or maladaptive behaviour and have certain basic emotional needs that must be met by the patient's context in order to facilitate further development.

Results/Aims The concept of emotional development has been used in our setting for several years. Recently we discovered that the model of Haim Omer adds a lot of value to our work as well.

Whereas the model of Anton Dösen focusses on the patient and our adjusted approach, the model of Haim Omer supports caregivers in coping with challenging behaviour and remaining a strong anchor point. We started integrating these two models.

Conclusions Our working experience tells us that integrating these models offers a strong base for working with our patients with complex problems.

From Science to Practise By using and integrating these two models we aim to offer our patients a treatment environment that is adjusted to their emotional level and with avoidance of violence. Simultaneously with working together with the patient's familiar network to regain strength in their daily life.

An integrative framework: New authority and emotional development

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12Multiversum

Keywords the new authority, emotional development, psychiatric hospital

Background We aim to find the best environment to offer treatment to our patients. By integrating two different models in our daily work, we try to optimize the relation between caregivers and patients. These models are : the new authority from H. Omer and emotional development from A. Dösen.

Methods Since several years we organize internal trainings for all caregivers about emotional development. Two years ago we started with an additional training about the model of new authority.

Last year a small taskforce started to integrate both models of Haim Omer and Anton Dösen into one. Furthermore we tried adjusting it for the context of working with people with intellectual disabilities. This training is now standard for all of our caregivers. On a monthly basis we organize a peer-to-peer coaching discussing cases where we have implemented the model.

Results/Aims We aim to give our caregivers a strong base of what the emotional need of our patients is and how to deal with challenging behaviour in a non-violent manner. We expect our staff to feel more assured working in this manner with our challenging audience. We keep monitoring the effect it has on our staff.

Conclusions Our working experience tells us that integrating these models offers a strong base for working with our patients with a range of complex problems.

From Science to Practise By using and integrating these two models we aim to offer our patients a treatment environment that is adjusted to their emotional level and with avoidance of violence. Simultaneously with working together with the patient's familiar network to regain strength in their normal daily life

Symposia seven (SoS-7 E/OS)

Topic: Legal and Forensic Issues, Restraints

Vulnerabilities of Prisoners with Autistic Traits

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Keywords Autism spectrum conditions, Autistic traits, Mental health, Prison, Screening

Background There is increasing recognition of people with autism spectrum disorders (ASD) across the criminal justice system. Prevalence studies of prisoners found rates of 1 to 4% for ASD with rates up to 18% in specialist juvenile courts. More recently there has been increasing recognition of the vulnerabilities of offenders with ASD including their risk for self-harm behaviour and mental illness.

Methods A cross-sectional study of 240 prisoners who screened positive for autistic traits and those diagnosed with an autism spectrum disorder were compared to prisoners who screened negative for autistic traits and other neurodevelopmental disorders on indicators of suicide related and self-harm behaviours, mental illness and substance use using the Mini International Neuropsychiatric Interview (MINI).

Results/Aims Prisoners screening positive with autistic traits were significantly more likely to have thought about self-harm in the past month and to have reported attempted suicide during their lifetime. In addition, those screening positive with autistic traits were significantly more likely to suffer from depression, anxiety disorders and antisocial personality disorder

Conclusions Prisoners with autistic traits appear more vulnerable to reporting self-harm thoughts and to a range of mental disorders than neurotypical prisoners. This strengthens the case for increased awareness and access to screening and subsequent diagnosis of ASD for this group of prisoners.

From Science to Practise This research has created awareness of the needs of autistic people in prison and discussion on appropriate intervention.

People with intellectual disability within Court Liaison & Diversion Services: characteristics & vulnerabilities

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Keywords Intellectual Disability, Neurodevelopmental disorders, Court, Forensic, Criminal Justice System, Vulnerable defendants

Background There is research highlighting a significant number of adults with intellectual disability within prison settings with an increased risk for co-morbid mental disorder. However, there is little evidence on the specific characteristics and vulnerabilities of defendants with intellectual disability when presenting to the Criminal court system.

Methods This is a retrospective data analysis of routine administrative data collected by the Liaison and Diversion services across five criminal magistrates' courts in London, England. Data were analysed on those identified through screening to have intellectual disability in order to compare with those defendants identified to have only a mental illness.

Results/Aims 9088 defendants were identified through the database with 349 (4%) of the total identified to have intellectual disability with just under 16% (n=55) of those with intellectual disability being female. Data will be presented on rates of identified psychiatric disorder and self-harm risk. There was no significant difference in rates of schizophrenia and depression between two groups. The group of defendants with intellectual disability had significantly higher current suicide/self-harm risk using chi-square analysis test reporting at the 0.05 level.

Conclusions The findings confirm the presence of small but significant number of defendants with intellectual disability presenting to Court Liaison & Diversion services. The implications of the findings will be discussed.

From Science to Practise This paper increases awareness of defendants with intellectual disability and their vulnerabilities to guide practice.

People with intellectual disabilities views on support following court contact

Ali S2, Chaplin E2, Tate-Marshall², Childs, J5, J. McCarthy^{1,2,4}, Harvey D2, Forrester A1,3

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Keywords Intellectual disability, court, service-user experience

Background This presentation explores the experiences of defendants with intellectual disability and their contact with criminal justice services targeted at vulnerable people.

Methods The study utilised a focus group to obtain qualitative data about criminal justice experiences. It aimed to answer the following research questions: 1.If you could set up a support group for people with intellectual disability what would it do? How would you get people to join? 2. What support would you like to see before and after appearing in court routinely available for people with intellectual disability?3. What do you think court and health staff need to know about intellectual disability to ensure fair sentencing and support for people being sentenced

Several questions were asked exploring areas for consideration related to service development. Data was recorded by hand, coded, and subsequently analysed using thematic analysis.

Results/Aims Five overarching themes (1. Staff skills & training 2. Accurate information & explanation; 3. Developing the group; 4. Nature & content of the group; 5. The Court environment) were found to be highly salient when answering the research questions.

Conclusions Whilst developing engaged and maintain engagement in services. services targeted at vulnerable defendants are commendable and necessary, it is also important to consider how such individuals are supported and barriers to entry.

From Science to Practise This study has revealed the importance of engaging service-user expertise in developing targeted criminal justices.

Thanks to Keyring Living Support Networks.

People with intellectual disabilities in prison and court settings in the UK.

Chaplin E2, J. McCarthy^{1,2,4}, Tate-Marshall², Ali S², Childs, J⁵, Harvey D², Forrester A^{1,3}

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Keywords Attention Deficit and Hyperactive Disorder, Autism Spectrum Disorder, Court Mental Health Liaison and Diversion, Intellectual Disability, Neurodevelopmental Disorders

Background This symposium examines mental health and awareness of intellectual disability in the UK criminal justice system. This first presentation describes the introduction of a specialist neurodevelopmental team into an existing court mental health liaison and diversion service.

Methods This study examined referrals of defendants with neurodevelopmental disorders over 30- months at a London Magistrates' Court following the introduction of a court mental health ND service (CMH+ND). Baseline data relating to mental disorder from the pre-existing liaison and diversion service were collected and compared with data collected following the introduction of the CMH+ND using the existing minimum mental health service dataset. The pathway of the CMH+ND is also described.

Results/Aims Of 19,422 cases that entered the court during the 30-month study period, 829 (4.3%) were referred to the CMH+ND. Of these, 79 (9.5%) had an identified ND. The CMH+ND detected higher rates of depression in defendants with ND compared to those in the CMH.

Conclusions It is possible to successfully integrate ND expertise into existing liaison and diversion services, using a multi-agency model, and this service enhancement demonstrated some modest evidence of service effectiveness, including an increase in the detection of comorbid mental illness and risk of self-harm/suicide, and a reduction in custodial remands.

From Science to Practise This study describes the findings from implementing a specialist NC liaison and diversion service.

Identifying and managing intellectual disability in prisons

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Keywords Intellectual disability, prison. Mental illness, self-harm, suicidality

Background In the UK, intellectual disability is not routinely screened for prison. The consequence is that this group of people may not be identified and not receive the support they require. This study aimed to examine mental health and offending characteristics of intellectual disability prisoners.

Methods The study used the LDSQ to screen 240 prisoners for Intellectual Disability and compared them to a group of prisoners without intellectual disability or significant traits of neurodevelopmental disorder.

Results/Aims Eighteen prisoners were identified with intellectual disability following screening. Prisoners with intellectual disability were significantly more

likely to have comorbid mental illness and 25% had thought about suicide in the last month with 63% having attempted suicide in the past. Prisoners with intellectual disability were less likely to be from a black or minority ethnic background, be over 35 years old and have been single, no qualifications, homeless or unemployed before coming into prison and housed in the vulnerable prisoners' wing.

Conclusions There are significant numbers of people with an unrecognized intellectual disability in the prison system. Equity of service for prisoners with intellectual disability needs to be a priority given vulnerability to poor mental health, self-harm, and suicidality.

From Science to Practise This study has shown increased rates of mental health problems and thoughts of suicide and self-harm. This study has implications on how we identify and assess this group

[Symposia eight \(SoS-8 E/OS\)](#)

[Topic: Ageing/Lifespan](#)

The use of biomarkers for the diagnosis of Alzheimer's disease (AD) in Down syndrome (DS)

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Keywords Alzheimer's disease, Down syndrome, biomarker, neurofilament light (NF-L), Amyloid β , Tau

Background While the development of direct cognitive assessments presents a significant advantage over the sole use of informant based interviews for the diagnosis of dementia, their applicability is limited in individuals with moderate to severe intellectual disability and selectivity is impaired by psychiatric co-morbidity. Biomarkers objectively monitoring the degree of neuronal loss accompanying a decline in cognitive function will aid diagnosis if they are a) specific for the process of neurodegeneration, b) highly sensitive, c) minimally invasive to obtain and d) carefully validated.

Methods Here we will review data on the use of plasma neurofilament light as a promising marker to monitor the neurodegenerative process in individuals with DS [2] and discuss emerging data on the dynamics of plasma A β 40 and A β 42 as well as Tau protein in ageing DS individuals.

Results/Aims Availability of CSF biomarkers from individuals with DS is limited, mainly due to the invasiveness of lumbar puncture. Ultrasensitive assays have facilitated the analysis of plasma markers. They are easy to obtain and therefore allow for intraindividual longitudinal analysis. The use of

plasma neurofilament light is as a promising marker to monitor the neurodegenerative process in individuals with DS.

Conclusions Further longitudinal studies should elucidate the association of changes in plasma biomarkers, brain atrophy, amyloid deposition and clinical course of the disease

.From Science to Practise The use of plasma biomarkers might be a promising marker for the diagnosis of Alzheimer's disease in individuals with Down's Syndrome.

German Translation and Validation of the CAMDEX-DS

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Keywords neuropsychology, cognitive assessment, CAMDEX-DS, dementia, Down's Syndrome

Background The "Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities" (CAMDEX-DS) was developed to diagnose Alzheimer's disease in Down's Syndrome (DS) and consists of an informant interview and a cognitive test battery (CAMCOG-DS). Aims of this presentation are to evaluate psychometric criteria of the German version and to show implications for a revised version.

Methods 56 adults with DS, 19 - 65 years, most with mild or moderate intellectual disability. The informant interview, the CAMCOG-DS and the Severe Impairment Battery (SIB) were applied. Dementia was diagnosed according to ICD-10 criteria in the CAMDEX-DS and convergent validity was evaluated including further clinical information (e.g., history, neurological assessment or neuroimaging).

Results/Aims Agreement between diagnosis in the CAMDEX-DS interview and clinical diagnosis was 80%, (specificity: 93%, sensitivity: 17%). A complete CAMCOG-DS score was obtained in 84% of all participants. Convergent validity between CAMDOG-DS and SIB as well as retest-reliability were low to acceptable, interrater-reliability was substantial to excellent. Further psychometric properties were good to excellent.

Conclusions The CAMDEX-DS informant interview is useful to exclude dementia, but shows low sensitivity when used as single instrument. The CAMCOG-DS is recommended for neuropsychological assessment in

intellectual disabilities. Critical aspects of the current version will be improved in the revised CAMDEX-DS-2.

From Science to Practise People with DS have a very high risk to develop Alzheimer's dementia. Providing validated instruments in different languages might lead to a more accurate assessment and treatment in this patient group.

Detection of dementia in individuals with intellectual disability using the DTIM - preliminary results

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Keywords dementia, intellectual disability, neuropsychology, diagnosis

Background Individuals with intellectual disability are at risk of developing dementia, yet the assessment of dementia remains challenging. The Dementia Test for Individuals with intellectual disability (DTIM) consists of a neuropsychological test battery and an informant-based questionnaire. We examined whether the DTIM identifies individuals with dementia correctly.

Methods Patients with intellectual disability at risk for developing dementia (n=104) were recruited to be tested three times at a 6-month interval. Multi-professional case conferences were conducted to confirm (n=21) or exclude (n=83) the suspicion of dementia. Neuropsychological assessment was performed by a trained clinical neuropsychologist, who was blind to the diagnosis. We compared the results of the baseline assessment (T1) and third assessment after 12 months (T3), expecting individuals with dementia to show a decline in test scores and demonstrate more behavioural symptoms than those with no dementia

Results/Aims Patients with dementia showed lower neuropsychological test scores than those without dementia at T3 ($p=0.02$). No significant changes in test scores after 12 months (T1 - T3, $p=0.09$) was found. Caregivers reported more behavioural symptoms for patients with dementia than for patients with no dementia at T1 and T3 ($p < 0.01$).

Conclusions Patients with dementia did not show a decline in test scores, but presented more behavioural symptoms. The test's sensitivity could be affected by the heterogeneity of cognitive abilities in the sample.

From Science to Practise Diagnosing dementia early is important for planning services and providing support. A standardised instrument for individuals with intellectual disability is essential to detect a cognitive decline early.

Dementia in persons with intellectual disability – a rare condition or of everyday relevance?

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Keywords dementia, review, clinical presentation, diagnostic workup, treatment

Background In Germany, 1% of general population has an intellectual disability. Reaching an age of more than 60 years is a relatively new phenomenon in Germany. Most important reason is better medical and social support.

Methods The results from a review of the current literature and observations of our out clinic patients with more than 1000 outpatients will be presented.

Results/Aims With increasing age, the incidence of dementias increases as well, in persons with intellectual disability in a disproportionately high number. With increasing degree of intellectual disability, the clinical picture gets more and more different, starting with decrease in everyday functioning, challenging behaviour or depressive symptoms. “Typical” symptoms mostly appear late in progress of the disease. Persons with Downs Syndrome are affected much more often and earlier in life.

Neuropsychological tests used in the general population are unsuitable for these patients due to missing standardized reference parameters.

Comprehensive treatment for these persons needs special approaches.

Knowledge from literature is poor.

Conclusions Knowledge about dementia in persons with intellectual disability is incomplete. With the data available support for people with dementia and intellectual disability can be offered.

From Science to Practise By understanding the underlying mechanisms of dementia in people with intellectual disability, support can be optimized and quality of life increased.

Assessment of dementia in a clinical sample of persons with intellectual disability

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Keywords dementia, intellectual disability, neuropsychology, memory, diagnosis

Background Due to the increasing life expectancy of persons with intellectual disabilities, assessment of age-associated disorders, such as dementia, has become important.

Methods In a clinical setting, people with an intellectual disability with and without dementia were assessed retrospectively using the Neuropsychological-Test-Battery (NTB) and the Dementia-Questionnaire-for-People-with-Learning-Disabilities (DLD) at two different times to analyse neuropsychological changes and diagnostic validity. One group (n=44) was assessed with both instruments while the DLD was applied in 71 patients.

Results/Aims Thirteen months after the first assessment, in the NTB (N=44) only patients with dementia (n=26) showed a decline in the NTB total score and three subtests "following simple commands", "object learning", and "delayed recall". ROC analysis revealed a diagnostic sensitivity of .67, a specificity of .81. In the DLD group (n=71), only those with dementia displayed a decrease in the cognitive and social scale; diagnostic sensitivity and specificity values were low (.61/.63).

Conclusions Neuropsychological assessment was sensitive to detect cognitive changes over time. Sensitivity values of both instruments suggest a reassessment at a later time point.

From Science to Practise Neuropsychological assessment is useful for detecting dementia in individuals with intellectual disabilities.

[Symposia nine \(SoS-9 E/OS\)](#)

[Topic: Emotional Development](#)

Validity analysis and clinical impact of the Scale of Emotional Development-Short

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Keywords Challenging Behaviour, Developmental Neuroscience, Emotional Development, Mental Disorders

Background: Persons with an intellectual disability are highly vulnerable for mental health problems. Recognition of their individual level of emotional development (ED) is essential for optimal treatment and support. The presented studies aim to analyse validity and clinical impact of the Scale of Emotional Development-Short (SED-S).

Methods: Adults with a mild to profound intellectual disability were assessed with the SED-S. The item validity (1) and the clinical impact of the SED-S analysis on (2) behavioural level, on (3) psychiatric disorders, specifically on (4) depression was evaluated.

Results: (1) The item validity varied in the 200 examined items. (2) The severity of challenging behaviours decreased in persons with higher levels of ED. Different types of challenging behaviour were delineated according to the level of ED. (3) The rates of different mental disorders differed according to the level of ED. (4) Acute depressive episodes decreased the level of ED.

Conclusion: Data analysis highlighted individual qualities as well as shortcomings of each item of the SED-S. The level of ED predicts challenging behaviour and different mental disorders.

From Science to Practice: Improvement of the SED-S on item level helps to assess more accurately the level of ED in persons with intellectual disability. Assessment of the level of ED is supportive in the diagnostic assessment of persons with challenging behaviours and/or mental disorders.

Disclosures Tanja Sappok receives royalties from different publishers, e.g. Hogrefe and Kohlhammer.

The impact of depressive episodes on the level of emotional development in adults with intellectual developmental disorder

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Keywords: Developmental Neuroscience, Emotional Development, Mental Disorders

Background: People with an intellectual developmental disorder (IDD) are vulnerable for affective disorders. Affective disorders may also have an impact on socio-emotional brain functions and thus on the overall level of emotional development (ED). In this study, we aim to examine the influence of depressive episodes on the level of ED in adults with an IDD.

Methods: The level of ED will be assessed in a pre-post-design. A structured interview using the Scale of Emotional Development-Short (SED-S) will be conducted to assess the current level of ED. Furthermore, the severity of the depressive episode is assessed by using different Questionnaires: Glasgow Depression Scale (GDS), Glasgow Anxiety Scale (GAS), Beck's Depression Inventory (BDI-II) and the Clinical Global Impression Scale of Severity (CGI-S). The assessment takes place during an occurring depressive episode (TP 1) and after remission (MP 2).

Results: First results indicate a decline of the level of ED in acute depressive episodes. All patients with depression are recruited from the study site and the instruments above will be applied. The first results will be presented at the conference.

Conclusions: During an acute psychiatric disorder, the level of ED may differ from the results obtained in healthy periods. This should be acknowledged in treatment and support.

From Science to practice: To ensure an adequate support it should be acknowledged that the level of ED and therefore the specific needs may differ depending on the mental health status.

Disclosures: Tanja Sappok receives royalties from different publishers, e.g. Hogrefe and Kohlhammer.

Seed the SED-S: does emotional development predict psychiatric disorders in people with intellectual disability?

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Keywords: Emotional Development, Developmental Neuroscience, Mental Disorders

Background: People with intellectual disability often show delays in emotional development (ED) and are highly vulnerable for mental health problems. This study aims to investigate the associations of the level of emotional development (ED) and psychiatric disorders in people with intellectual disability.

Methods: Overall, 485 adults with intellectual disability with (n = 337) and without (n = 148) psychiatric disorders were assessed with the Scale of Emotional Development – Short (SED-S). Multiple linear regression analysis was used to evaluate the reciprocal associations of ED and specific psychiatric diagnoses.

Results: The severity of intellectual disability was inversely correlated with the level of ED ($r_s = -.636, p < .001^*$). Both, the severity of intellectual disability ($F(1, 483) = 297,5, p < .001^*, R^2 = .381$) and autism spectrum disorders ($F(1, 483) = 66,36, p < .001^*, R^2 = .120$) were predicting lower levels of ED.

Moreover, lower levels of ED were associated with schizophrenia ($p < .05^*$), whereas anxiety disorder, dissociative disorder, personality disorders and substance abuse disorder predicted higher levels of ED (all $p < .05^*$). Notably,

the level of ED had no impact on clinical manifestation of affective disorders ($p > .05$).

Conclusions: Assessment of the level of ED is supportive in the diagnosis of mental disorders in persons with intellectual disability. Further analysis will explore whether the specific levels of ED can delineate the repertoire of the subsequent mental illness.

From Science to Practise: The recognition of the specific patterns of delays in ED contributes to a better understanding of the pathogenesis of the mental illness in people with intellectual disability.

Disclosures: Tanja Sappok receives royalties from the book publisher Hogrefe and Kohlhammer.

Behavioural Phenomena in Persons with an intellectual disability according to Emotional Development

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Keywords: Challenging Behaviour, Developmental Neuroscience, Emotional Development

Background: Intellectual developmental disorders (IDD) are grouped within the neurodevelopmental disorders. The complex relationship between structural and functional brain connectivity during development may provide a crucial background for a better understanding of behaviours shown in persons with IDD.

Methods: The behaviours of 185 adults with IDD were systematically assessed with the Aberrant Behaviour Checklist (ABC) and the Modified Overt Aggression Scale (MOAS). The association of different behaviours with various emotional reference age groups as assessed with the Scale of Emotional Development – Short (SED-S) was analysed to deduce specific behavioural patterns.

Results/Aims: Overall, the severity of challenging behaviours decreases with higher emotional reference ages. In SED-S-1 (reference age: 0-6 months), the behaviours of a person appeared disconnected and showed high scores in social withdrawal, lethargy, and irritability. Persons functioning in SED-S-2 (7-18 months) scored highest in irritability and physical aggression (disintegrated), while those in SED-S-3 (19-36 months) exhibited the disorganised type

characterized by defiant and socially inappropriate behaviours. Persons with an emotional reference age of 4-7 years (SED-S-4) showed inappropriate speech, verbal self-regulation, and depressive-like behavioural aspects (searching for identity).

Conclusions: The level of emotional development is a strong predictor of challenging behaviour in individuals with IDD with distinct behavioural patterns according to the respective reference age group.

From Science to Practice: The emotional development approach may support caregivers to better understand the behaviours of persons with an ID and clinicians differentiate behavioural problems from psychopathological symptoms.

Disclosures: Tanja Sappok receives royalties from different publishers, e.g. Hogrefe and Kohlhammer.

Symposia ten (SoS-10 E/OS)

Topic: Challenging Behaviour

Who challenges whom? Effects of systemic interventions in the field of intellectual disability and challenging behaviour

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Keywords challenging behaviour, mental disorder, acute psychiatry, systemic approach, multi-carer- system

Background Adults with intellectual disability are at risk for mental disorders, aggressive behaviour constitutes the most common reason for psychiatric consultation or admission. A well implemented evidence- based systemic training program for general psychiatry named SYMPA (Systemic Methods in Acute Psychiatry) was adapted to the field of intellectual disability and undertaken with pedagogic and psychiatric staff.

Method During a two-year training multi-disciplinary teams of both a psychiatric hospital (in- and outpatient service) and nine residential care homes were trained in systemic theory and practice. Longitudinal studies investigated the impact of the training on various factors of mental wellbeing of patients and carers. Also ways of preventing and coping with aggressive behaviour were investigated.

Results While trainees valued SYMPA-ID to be useful quantitative studies failed to show any significant impact on the enquired variables. Qualitative data analysis led to a compilation of 43 interactive strategies for reducing aggressive behaviour.

Conclusions/aims Adults with intellectual disability and mental disorder usually are supported by multiple carers following system-immanent logic and rules. Systemic interventions facilitate respectful cooperation, enable joint goal planning and make use of the multi-systemic expertise at eye-level. The analysed strategies for managing aggressive incidents underline the relevance of systemic attitudes and techniques. Further studies should re-engage in analysing the impact of systemic interventions on the mental wellbeing of patients or professionals.

From Science to Practise The symposium highlights opportunities and constraints of SYMPA-ID from a group home's point of view and illustrates systemic issues to be considered within an outpatient psychiatric setting. Systemic thinking brings forth supportive collaboration within the multi-carer system which usually occurs in case of serious behavioural problems.

Maintaining appreciation in a strained psychiatric consultation: benefits of the systemic approach

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Keywords intellectual disability, psychiatric outpatient service, systemic attitude, appreciation, systemic contracting

Background Psychiatric treatment quite often is a difficult issue for carers of people with intellectual disability, especially for relatives. For many reasons there are a lot of ambivalent, disrespecting, rejecting and devaluating emotions. A professional attitude of appreciation can barely be maintained in such emotionally distressed situations.

Method SYMPA offers systemic tools to overcome challenging interactions in psychiatric consultations. Especially slowing the pace for an accurate clarification of concerns can be helpful because the bigger the ambivalence of carers or patients the more undefinable their requests are. Within the contracting process a joint understanding and appreciation of affects and needs grows. In valuing any concerns the potentials and also the limits of the psychiatric treatment get clear.

Results The attitude of appreciation combined with an accurate clarification and negotiation of concerns helps professionals to withstand strong emotions and offending behaviours of clients.

Conclusions Appreciation as a professional attitude seems to be evident in psychiatric consultation. But in the field of intellectual disability and mental illness a valuing position often is corroded by a mutual transfer of strong

emotions and pressure. The capability to adopt an appreciative position should be reflected and recovered throughout the whole therapeutic process.

From Science to Practise SYMPA-ID offers several techniques to facilitate appreciative cooperation between clients and carers. Like all therapeutic approaches systemic interventions have to be reflected and adjusted permanently in a psychiatric service for people with intellectual disability.

From challenge to change: effects of a systemic intervention in a group home setting

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Keywords Challenging behaviour, systemic training, strategies to prevent and cope with challenging behaviour

Background With regard to people with mild intellectual disability and challenging behaviour usual pedagogic or therapeutic concepts for intellectual disability often do not work. The presentation illustrates the story of a young resident of a group home who was in danger of being discharged by the institution because of his massive inadequate and sexualised behaviour.

Methods The leader of the residential group home the guy lived in participated in the SYMPA training program and briefed her staff in systemic thinking. A new pedagogic concept incorporating systemic attitudes and methods was developed and installed in cooperation with the multi- carer-system of the client. The most important method was an accurate clarification and negotiation of concerns and requests of the client, his carers, relatives and psychiatric staff. This was followed by interviews with the client and the use of reflecting teams.

Results/Aims Due to the changed attitude of the staff members and the integration of relevant carer- systems of the client, a new concept could be created that supported the client in gaining more quality of life and being able to stay in the institution. The residential staff got motivated in dealing with behavioural problems and considered challenging behaviour as a challenge to step up the plate and not as a burden.

Conclusions With regard to the frequent turnover of pedagogic staff in the field of intellectual disability the sustainability of SYMPA depends on a continuous implementation of systemic techniques for maintaining the achieved standard in posture and assistance.

From Science to Practice The jointly developed and implemented SYMPA- concept paid off for the residential staff because they created a shared

language and a solution-focused action plan. It also paid off for the client: he still lives in the same group home

Adopting systemic methods in psychiatric contexts: Results from the German research project SYMPA-ID

Meike Wehmeyer

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Keywords Aggressive behaviour, systemic training, mixed-method research, strategies to prevent and cope with challenging behaviour

Background Adults with intellectual disability are at quite high risk for mental disorders whereas aggressive behaviour constitutes the most common reason for psychiatric consultation or admission to the hospital. A well implemented and evidence-based systemic training program for general psychiatry named SYMPA (Systemic Methods in Acute Psychiatry) was adapted to the field of intellectual disability and was undertaken with multi-disciplinary pedagogic and psychiatric staff.

Methods The training was accompanied by a complex prospective study design. Similar to prior SYMPA research quantitative data was collected with regard to parameters of wellbeing both of patients and staff, e.g. frequency of aggressive behaviour, use of restrictive measures, carer's level of burn-out. Ways of preventing and coping with aggressive behaviour were investigated via semi-annual interviews with psychiatric patients as well as their private and paid carers.

Results/Aims In contrast to previous findings quantitative studies failed to show any significant effect of the SYMPA training. Qualitative data analysis of nearly 200 interviews resulted in a compilation of 43 strategies of (systemic) attitudes and techniques. Interrater-reliability has proved to be high, validity could be verified.

Conclusions Interviews with trainees indicated that institutional issues (staff shortage, changes in management, enduring conflicts with superiors) had a potential impact on the failed effects. The implementation and sustainability of SYMPA depends on the power and stability of the staff.

From Science to Practise Professionals in the field of intellectual disability responded well to the compilation of strategies and initiated using the list for action planning, self-reflexion and supervision. The referring doctoral thesis was decorated with two research awards.

Symposia eleven (SoS-11 E/OS)

Topic: Models of Care and Support

Treatment model for adults with intellectual disability and MH problems: a continuum of inpatient and outpatient care

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Keywords Models of Care and Support; Emotional Development; Mental disorders

Background Mental health problems of people with intellectual disability are complex and thus request a flexible, differencing and matched treatment and care programme. A dynamic care continuum is necessary in order to achieve this.

Methods/aims A clinical and organisational model of need-driven care is demonstrated. The different units and the connections between them are introduced.

Results The principle of subsidiarity and the empowerment of the natural and professional context are essential in the treatment model.

Conclusions The symposium about matched, inpatient and outpatient care starts with a presentation of a clinical and organisational model within a psychiatric hospital.

From Science to Practise Based upon theoretical concepts as emotional development, a clinical treatment practice is presented.

How to treat/support adults with intellectual disability and MH problems and their environment? An example of matched care

1 Filip Morisse, 2 Suzan Laureys, 3 Saskia Rigolle, 4 Leen De Neve

1, 2, 3, 4 Psychiatric Centre Dr. Guislain, Ghent, Belgium

Keywords Models of Care and Support, Adolescent, Emotional Development, Mental Disorders

Background “De Steiger”, Psychiatric centre Dr. Guislain (Ghent, Belgium) and has a care programme for people with intellectual disability and mental health problems. De Steiger offers both residential and outreaching treatment and support.

Methods/aims A clinical and organisational model of care is presented. The admission unit for short psychiatric care, the admission unit for youngsters (16-25) and the outreaching support of “De Steiger” are illustrated in case studies.

Results The organisation of the care programme facilitates flexible trajectories and matched care, but there are also challenges.

Conclusions An example of matched care is highlighted in this symposium.

From Science to Practice Based upon theoretical concepts as emotional development, a clinical treatment practice is presented.

Case study: man with moderate intellectual disability, epilepsy and psychosis admitted in a short term psychiatric unit

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Keywords Models of Care and Support, Emotional Development, Mental Disorders

Background M. is frequently admitted in the unit, each time for a few weeks. M. is 50 years old and lives in a home for people with intellectual disability. He has a moderate intellectual disability and uncontrolled epilepsy. The admissions are required because M. has frequent psychotic episodes, often related to his epileptic condition. In a psychotic episode M can be aggressive or run away.

In the short term unit patients are admitted for 1 to 6 weeks. This is often sufficient to stabilise the psychiatric crisis, to provide rest for the patient and his context, to attune the medication and to enable the context to continue the care. Patients can be admitted fast, mostly within a week. The short duration reduces the barriers and creates an active mentality. The unit provides a safe environment with focus on basic needs and low expectations.

Methods The case study of M. and the received psychiatric care will be examined.

Results The admissions ensure that M. can stay in the home despite his psychiatric and medical problems.

Conclusion This case illustrates the necessity and value of the unit for short term admissions within a continuum of care for patients with complex (psychiatric) needs.

From Science to Practise Based upon theoretical concepts as emotional development, a clinical treatment practice is presented.

Case study of an 18-year-old female (mild intellectual disability and ASD) admitted in the admission unit for youngsters

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Keywords: Models of Care and Support, Adolsecent, Emotional Development, Mental Disorders

Background: L. is a young adult with mild intellectual disability and ASD. Her parents and professional caretakers would describe L.'s behaviour as challenging: verbal aggression, self-injurious behaviour, suicidal ideation, ... L. demanded admissions to psychiatric programs. Parents and professional caretakers tried to hold off those admissions. The situation escalated and Laura attempted suicide.

Methods/aims: The case of L and the received psychiatric care will be examined.

Results: In the admission unit for youngsters, we focus on mental health during the transition from adolescence to adult life. This psychologically vulnerable group is often confronted with a society and care system that is not attuned to their desires and needs. How can we establish a continuum of care for them? And how can we encourage them to explore their growth potential and to experiment within a safe environment?

Conclusions: This case illustrates the necessity and value of the admission unit for youngsters.

From Science to Practise Based upon theoretical concepts as emotional development, a clinical treatment practice is presented.

Outreach trajectory with the context of a woman with mild intellectual disability and neurodevelopmental disorder

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Keywords Models of Care and Support, Emotional Development, Mental Disorders

Background Outreach – a mobile team for people with intellectual disability and mental health problems – is part of the care programme of De Steiger. The aim is to support and strengthen these people and their environment and – when it is possible, to avoid residential admissions.

Methods case-study of an outreach-trajectory

Results K. is a woman with mild intellectual disability and neurodevelopmental disorder. She lives on her own, and is supported by family and professional caregivers. The environment is confronted with extreme claiming and persistent behaviour, with panic attacks and stalking. It seems as if nothing helps, and they all have the idea that they tried everything. They are exhausted and asked for help. Questions arise, such as “is living on her own even possible for this woman?”, “doesn't she need more support?”, “only living in a home will be possible, with a lot more support”...

Conclusions Outreach is a mobile team that focusses on empowering the context in the care for the patient. During the Outreach trajectory, we

investigate hypotheses, dynamics, to attune care to the needs of patients and their context.

From Science to Practise Based upon theoretical concepts as emotional development, a clinical treatment practice is presented. Disclosure

Symposia twelve (SoS-12 E/OS)

Topic: Mental Disorders

Neuropsychological outcome in adults with FASD and intellectual and developmental disorder

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Keywords: FASD, 4 Digit Diagnostic Code, neuropsychological profile, CNS Score, microcephaly

Background: Intellectual and developmental disorders (IDD) are common with people with FASD in about one third of the patients. If IDD is known, further neuropsychological tests are often omitted; they are not needed to diagnose FASD. Further tests are the basis for treatment and counselling.

Methods: In this retrospective study, we will present the results of the neuropsychological

performance of our FASD outpatients. From 2016-2021, 84 patients underwent an FASD diagnostic process according to the 4 Digit Diagnostic Code. Standardized neuropsychological tests were administered to evaluate the CNS-score, including a verbal learning and memory test (VLMT), the developmental test of visual perception for adolescents and adults (DTVP-A), a word fluency test, a computer-based test battery to test attention and executive functioning (TAP) and IQ-scores (WAIS-IV).

Results: 27 patients had an IDD compared to 34 patients with a learning disability and 17 patients with average IQ. 23 patients with IDD received a FASD diagnosis. All neuropsychological domains except for learning and memory were significantly more often deficient with people with FASD and IDD, half of this group displayed a heterogenous profile. Mostly impaired were visual perception, executive functioning and attention followed by maths, language and learning and memory. We found no correlation between overall CNS Score and microcephaly.

Conclusion: In IDD, additional testing should be included, but more individualized and more efficient.

From Science to Practice: Especially adults with FASD and a heterogenous neuropsychological profile are at risk to suffer from excessive demands by

others. Counselling based on test results can be helpful for individualized coaching.

Fetal Alcohol Spectrum Disorder (FASD) in Intellectual disability

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Keywords FASD, mental disorders, neuropsychological profile, childhood, adults

Background Fetal Alcohol Spectrum Disorder (FASD) is common in almost all societies. Though it having a high impact on social functioning, it is widely unknown in caregivers for persons with Intellectual disability. Moreover, there is not much research in this field yet.

Methods An overview over current literature and knowledge in persons with intellectual disability is given. Results from three outpatient clinics for persons with FASD will be presented. Therefore, the data from these clinics were analysed in regard to social functioning, possibilities and challenges in making the diagnosis and comorbid psychiatric disorders. A special focus is being put on suicidal ideation.

Results/Aims Making the diagnosis of FASD in this population is challenging but possible. If FASD is present, it has a multitude of consequences for the affected persons: it interferes with social and intellectual functioning and often results in comorbid mental illness. Suicidal ideation is common.

Conclusions It is crucial to be aware of the spectrum of special needs resulting from neuropsychological deficits and mental illnesses in these patients.

From Science to Practise The diagnostic process is being lined out and made transparent for the audience. The awareness for FASD in everyday practice will be raised. Hints for support in this condition will be developed from the presented scientific results.

Disclosures Disclosure author author 2: Royalties as a speaker/lecturer from FASD Deutschland e.V., schools and youth welfare service. Disclosure author

Fetal Alcohol Spectrum Disorder (FASD) in Children and Adolescents. Focussing on Invisible Impairments

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Keywords Fetal Alcohol Spectrum Disorder, Executive Functioning, Invisible
Impairments, Dissociated Intellectual Disability

Background One of the most impairing symptoms of a child/adolescent with
FASD proves to be the unrecognized and unconsidered variations of dissociated
intellectual abilities and disabilities in the children/adolescents concerned.
While some children and adolescents with FASD have a general intellectual
disability, a large number of children and adolescents with FASD have a strongly
inhomogeneous profile in the tested intelligence (i.e. with WISC-V). It is often
difficult for parents, care-takers, teachers and health professionals to deal with,
for instance, a neurotypical verbal intelligence on the one side and a severe
impairment of executive functions on the other.

Methods/Results/Aims/Conclusions Reporting from the work of the FASD out-
patient clinic of our department, we focus on the diagnosis and consideration of
variant intellectual functioning. It is one of the main means to ensure the
recognition of the present impairments and possibilities, thereby ensuring
participation in family and school life.

From Science to Practice Often it is the parents or caretakers themselves, who
are the first to realize, that their children need “something else”. With every
child or adolescent with FASD seen in our department, we have to start a new
communication process with the involved professionals of the youth welfare or
school system. Introduced is the common clinical pathway, which we follow.

Disclosures Royalties as a speaker/lecturer from FASD Deutschland e.V., schools
and youth welfare service.

Fetal alcohol spectrum disorder (FASD) – only relevant for children?

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Keywords: Review, FASD, Intellectual disability, challenging behaviour

Background: FASD is one of the most common reasons for antenatal acquired
mental and physical disorders. Mental and physical problems persist into
adulthood. Often unrecognized, caregivers are not aware of impact on
everyday life. Knowledge about FASD in intellectual disability is poor.

Methods: Current literature will be presented with special focus on
persons with intellectual disability. Experiences and data from our outpatient-
clinic for persons with intellectual disability will be presented.

Results/Aims: FASD has a multitude of implications for treatment and support in
persons with intellectual disability: it leads to various forms of challenging

behaviour, often refractory to treatment. Typical is good verbal expression in contrast to poor verbal understanding and executive functioning. Moreover, persons with FASD mostly have problems in processing and integrating new information resulting in poor performance in new or unknown situations. Knowledge about FASD for persons with intellectual disability is poor. On first view, many appear unaffected, but have a poor performance in everyday life. Others are more affected with more severe intellectual disability. They often show challenging behaviour refractory to treatment. They need a special approach with usage of “easy language”, more repetition and less topics per session. Sessions with persons with FASD and intellectual disability should be even shorter than in persons without FASD.

Conclusions: It is crucial to be aware of the special needs in persons with FASD to be able to provide an adequate support. FASD is common but often unknown in persons with intellectual disability.

From science to practice: By understanding the theoretical background and clinical implications of FASD in persons with intellectual disability, support, treatment of challenging behaviour and mental diseases can be much more efficient and focused.

Substance use, comorbid psychiatric disorders and suicide attempts in adult foetal alcohol spectrum disorder patients

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Keywords: FASD, substance use, suicide attempts, mental disorders

Background: Data on adult foetal alcohol spectrum disorder (FASD) patients and their mental health are rare. The purpose of the study was to describe substance use and comorbid psychiatric disorders and suicide attempts in adult FASD patients.

Methods: Structured clinical interview considering mental disorders and substance use were administered with patients attending a specialized FASD diagnostic service at a German university hospital.

Results: 120 adults (57 % male, 43 % female, age: M=26.2, SD 8.3, min 18 max 66)) with FASD were included. More than one third (37 %) fulfilled the ICD-10 diagnostic criteria for mild intellectual disability, 47 % were in the under-average IQ-range. Further 25 % fulfilled the criteria for a comorbid psychiatric disorder, 30 % reported at least one suicide attempt. With regard to substance

use, 62 % drank alcohol, 27 % smoked cannabis, 9.6 % used amphetamines, 4.3 % cocaine and each one patient heroin and methamphetamine in the previous 12 months. Five patients (4 %) were diagnosed with a substance use disorder. Conclusion: Mental retardation affects one third of the sample. Current alcohol use was lower than in the general population, but higher for cannabis and stimulants. Comorbid mental disorders and substance related disorders were considerably lower than in previous research.

From Science to practice: Therapy and counseling for FASD must be adapted to the often- accompanying intellectual disability. Substance use should be considered in FASD care settings. Adult FASD patient are a vulnerable group for suicide attempts.

[Symposia thirteen \(SoS-13 E/OS\)](#)

[Topic: Models of Care and Support](#)

Mental healthcare for adults with mild intellectual disabilities: Urgent care within out-of-hours GP services

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Keywords Out-of-hours care, Primary Health Care, Medical records, Care innovation

Background Patients with mild intellectual disabilities (ID) and mental health problems are more likely to request out-of-hours primary care than the general population. However, in the Netherlands mental healthcare is insufficiently available for patients who require urgent but not acute psychosocial care. A mild intellectual disability (ID) might be one of the underlying causes of the urgent care request. Incorporating a mental health nurse practitioner (MHNP) in out-of- hours general practitioner (GP) services may offer a solution to this problem. This research aims to investigate common mental health problems presented to the MHNP and identify contributing factors to these care requests.

Methods During a nine-month pilot study, a MHNP was implemented in in 3 out-of-hours GP services. Medical records of these MHNP consultations were collected and analysed, examining reported mental health problems and contributing factors, such as the presence of a mild ID.

Results The results presented will focus on the nature of mental health problems, contributing factors and characteristics of the patients consulting the MHNP in GP services.

Conclusion Findings provide insight into the needs and characteristics of people requesting out-of-hours primary mental healthcare, whether or not caused by the presence of an

From science to practice This study enhances knowledge regarding mental health issues and needs of people requesting out-of-hours primary care for psychosocial problems. More importantly it contributes to the realization of adequate out-of-hours care for people with psychosocial problems by offering adequate mental healthcare early in the care chain, providing patient- friendly healthcare and preventing aggravation of psychosocial problems.

Mental health care for adults with mild intellectual disabilities; Four studies using Dutch health data

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Keywords Primary Care, Mental Healthcare, Medical records, Health data

Background This symposium gives an up-to-date scientific overview on care provided to patients with mild intellectual disabilities (ID) and mental health disorders (MHD), based on medical records. Although people with ID suffer more MHD than people without intellectual disabilities, mental healthcare (MHC) for these patients is considered insufficient. Primary care is pivotal in MHC as early recognition and intervention prevent aggravation MHD and affects specialized MHC. However, to date, there is limited fundamental research in MHC. This symposium aims to elaborate on primary and specialized MHC provided to these patients and fill this knowledge gap.

Methods The four presented studies analyzed Dutch routine health data to examine MHD prevalence and utilized care. Each study used different retrospective databases, containing either regular or out-of-hours primary care data, or population-based MHC. In two cohorts linkage to national administration databases was used to identify people with mild intellectual disabilities.

Results Preliminary results of all studies showed that people with intellectual disabilities had different diagnostic mental health profiles and showed higher care use, such as more crisis interventions and more medication prescriptions. A substantial proportion of patients with mild intellectual disabilities was not registered as such in their medical records.

Conclusions There are significant differences in the prevalence of MHD and care provided between people with and without intellectual disabilities in primary

care and MHC. Mild intellectual disabilities is potentially under-recognised in all these fields.

From Science to Practice By using different cohorts of health data we attained a realistic insight into care provided to patients with intellectual disabilities and MHD. As this offers starting points for enhancement, this is a fundamental step towards improving MHC for patients with intellectual disabilities

Mental healthcare for adults with mild intellectual disabilities; a cohort study in Dutch mental healthcare

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Keywords Mental Health, Mental Disorders, Medical record, Population-based

Background People with mild intellectual disability suffer more mental health disorders (MHD) than people without intellectual disability. Mental Healthcare (MHC) practitioners indicate limited knowledge and experience to provide the care needed. Besides diagnosing MHD, identification of the intellectual disability itself is a challenge. **To date**, fundamental research in MHC on the prevalence of MHD in people with mild intellectual disability and the actual care provided to this group is limited. This study aims to fill this knowledge gap.

Methods All adult users of Dutch MHC between 2015 and 2017 were enrolled in a retrospective cohort study. Presence of mild intellectual disability was established by linking MHC data with social services and chronic care databases. Characteristics of new cases of MHC were analyzed and compared between patients with and without mild intellectual disability.

Results Linking databases identified 11,374 MHC patients with mild intellectual disability, and 525,162 patients without intellectual disability. Preliminary results showed people with mild intellectual disability in MHC had more diagnostic trajectories, had different diagnostic profiles, required more crisis interventions, and more psychiatric hospital admissions compared to people without intellectual disability. A substantial proportion of patients with mild intellectual disability did not have this characteristic noted in their MHC records.

Conclusions There are significant differences in the prevalence of MHD and provided care between people with and without a mild ID, in MHC. Mild intellectual disability is potentially under recognised among MHC patients.

From Science to Practice By linking datasets we were able to identify people with a mild intellectual disability who were not recorded by the MHC as such. This gives a more realistic insight into the care provided to people with mild intellectual disability in MHC.

Mental healthcare for adults with mild intellectual disabilities: a cohort study in Dutch primary care

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Keywords Primary Health Care, Mental Health, Drug prescription, Medical record

Background People with mild intellectual disability suffer more mental health (MH) disorders than people without intellectual disability and often do not receive appropriate mental healthcare. General Practitioners (GP) play a pivotal role in this care. However, there is limited fundamental research in primary care on the prevalence of MH problems in people with mild intellectual disability and actual GP care provided. This study aims to fill this knowledge gap.

Methods A retrospective cohort study is performed in the Primary Care Database of the Netherlands Institute for Health Services Research, covering 1.8 million listed Dutch citizens in the period of 1-1-2015 to 31-12-2018. Presence of mild intellectual disability was established by linking this Primary Care Database with databases on social services and chronic care. Characteristics were analyzed and compared between patients with and without mild intellectual disability.

Results/Aims Linking databases identified 11,887 adults with mild intellectual disability. Preliminary results showed that they had more registered MH illness episodes, with a higher prevalence of almost all types, compared to people without intellectual disability. Additionally, people with mild intellectual disability and MH illness episodes received more GP consultations, more medication prescriptions and more psychotropics. More detailed results will be presented.

Conclusions There are significant differences in the prevalence of MH illness episodes and primary care provided between people with a mild intellectual disability and without an intellectual disability.

From Science to Practice Linking datasets enabled us to identify people with a mild-ID who were not recorded by the GP as such. This more realistic insight into the primary mental healthcare provided to people with mild intellectual

disability and is a first step towards improving mental healthcare for patients with intellectual disability in general.

Mental healthcare for adults with mild intellectual disabilities: a detailed description of GP care

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Keywords Primary Health Care, Mental health disorders, Medication, Referrals, Medical records

Background Mental health problems are more common among people with intellectual disability. However, mental health care for this vulnerable group is insufficient. General practitioners (GPs) are increasingly confronted with this patient group and experience various challenges in providing health care to them. This study will compare the provided care for adults with and without intellectual disability consulting their GP for mental health problems.

Methods A retrospective cohort study using data of nine general practices with high data quality standards. Mental health problems included symptoms or complaints such as sleep disturbance, or feeling anxious as well as disorders such as depressive or anxiety disorders. Provided care included number of consultations, reasons for encounter, laboratory results, medication prescription and referrals. All care is specifically linked with the mental health problem and therefore detailed information on provided care is available.

Results The most prevalent mental health problems for persons with intellectual disability were tobacco abuse, sleep disturbance, feeling anxious or nervous, drug abuse and depressive disorder. Care provided by the GPs to patients with intellectual disability were compared to matched controls without intellectual disability. Patients with intellectual disability had less consultations at practice, and more home visits and telephone consultations after hours, more prescriptions with antipsychotics, and less referrals to primary care psychologist, and more referrals to a mental health institution.

Conclusions Awareness of these differences is the first step in improving mental health care for patients with intellectual disability

.From Science to Practise This unique data linking the mental health problem to the given care we provide valuable information on the actions of the GP in patients with intellectual disability

Symposia fourteen (SoS-14 E/OS)

Topic: Challenging Behaviour

Treatment of self-harming and suicidal behaviour in by adapted dialectical behaviour therapy

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Keywords Intellectual disability, adjusted dialectical behaviour therapy, emotion dysregulation, daily records

Background The impact on daily life of emotion dysregulation (in the form of self-harming and suicidal behaviour) in clients with intellectual disability is high. There is abundant evidence for the treatment of suicidal behaviour and self-harming through dialectical behaviour therapy in people with normal intelligence. Research into the effects of an adjusted DBT program for clients with intellectual disability is scarce. One element of DBT is the use of daily diary for the client to monitor his/her problem behaviour. This daily diary can be used to gain insight in the course of the behaviour over time, but also for research into the effects of the treatment program.

Methods Adjusted dialectical behaviour therapy (Skills System Julie Brown), group therapy, daily diary (basic emotions, need for self-harming and suicidal behaviour, the presence of self-harming and suicidal behaviour).

Results/Conclusions Insight in the effect of an adjusted DBT program for clients with intellectual disability and emotion dysregulation. Insight into the course of self-harming and suicidal behaviour and factors relating to increase or decrease of this behaviour. Conclusions will be presented and implications will be discussed.

From Science to Practise Emotion dysregulation in the form of self-harming and suicidal behaviour is a persistent problem. This leads to suffering in the person self and lots of time there is a chronic course. For persons with intellectual disability treatment there is often less options for treatment. Lighting in the complaints can give the person a greater quality of life.

The effectiveness of a personalized treatment for substance use disorder in people with Mild Intellectual Disabilities or Borderline Intellectual Functioning

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Keywords Substance Use Disorder, Mild Intellectual Disabilities, Borderline Intellectual Functioning, Personalized care, mHealth

Background The prevalence of Substance Use Disorder (SUD) in people with Mild Intellectual Disabilities or Borderline Intellectual Functioning (MID-BIF) is high and the consequences are severe. However, effective treatment for people with MID-BIF and SUD is lacking. We developed Take it Personal!+. This treatment aims to reduce substance use in individuals with MID-BIF and is based on motivational interviewing and cognitive behaviour therapy and personalized based on the client's personality profile. Furthermore, a mHealth application supports the treatment sessions. The effectiveness of this personalized MI-CBT program is tested.

Methods The effectiveness of Take it Personal!+ in decreasing substance use is assessed in a non-concurrent multiple baseline across individuals design comprising ten participants with MID-BIF and SUD. The participants were randomly allocated to one of the five baseline lengths (7–11 days). Substance use is assessed during baseline, intervention, and post-treatment phase using a daily diary method. The daily diary method was also part of the personalized treatment.

Results/Conclusions Visual analysis show promising results. Further results of the effectiveness of Take it Personal!+ will be presented. In addition, attention will be paid to how science and practice meet each other in the daily diary method.

From Science to Practise If the study shows positive results the care for individuals with MID-BIF and SUD will be improved. Besides, single case designs and the daily diary method fit well with the clinical practice, which makes it possible to conduct more research in clinical practice.

Physiological stress as early-warning signal for challenging behaviour in people with severe to profound intellectual disabilities

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Keywords severe to profound intellectual disabilities, challenging behaviour, physiological stress

Background Clients with severe to profound intellectual disabilities (SPID) and challenging behaviour (CB) and the professional caregivers that support them are vulnerable to experience high levels of stress. Both clients' and caregivers' stress is believed to impact the occurrence and maintenance of CB. We will present patterns of physiological stress preceding incidents of CB in a person

with SPID. Additionally, the interplay between the stress levels of the person and a professional caregiver is presented.

Methods Physiological stress is measured with the Empatica E4 in a person with SPID and CB and a professional caregiver. From the perspective of complex-systems theory, we test whether early-warning signals in clients' physiological stress predict transitions in the behaviour of the person. In addition, cross-Recurrence Quantification Analysis is performed.

Results/Conclusions Results show whether early-warning signals in physiological measures can be used to predict transitions in behaviour. Recurrence plots show the (de)synchronization between physiological stress levels of the client and the caregiver, as well as who is leading in the pattern of physiological stress prior to an incident of CB. Conclusions will be presented and implications will be discussed.

From Science to Practise Insights in the physiological stress levels of a client and caregiver may contribute to a reduction of CB and an improvement of both the client's and caregiver's safety and well-being in clinical practice.

Lessons about the feasibility of daily diary monitoring in youth with Mild Intellectual Disabilities / Borderline Intellectual Functioning

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Keywords Intellectual disability, Daily diary sampling, Substance use

Background Youth with mild intellectual disability (MID; IQ range 50–69) or borderline intellectual functioning (BIF; IQ range 70–85) often use alcohol, cannabis, and other illicit drugs. Compared to retrospective surveys, daily diary sampling via a mobile phone application has the potential to enhance ecological validity, minimize recall bias, and allow the study of microprocesses that influence individuals' behaviours in real-world contexts. Accurate assessments of behavioural processes depend on the feasibility of the method, i.e., if participants are compliant and deem it acceptable.

Methods We include a minimum of 35 participants between 14-30 years old with MID-BIF who receive one daily diary via their mobile phone for 60 consecutive days. Daily diary items span a range of emotional and behavioural problems. After the 60-day diary period we administer a structured interview to assess acceptability.

Results/Conclusions To use daily diary sampling in clinical practice and research on this target group, we explore its feasibility, validity, and reliability.

Conclusions will be presented and implications will be discussed.

From Science to Practise Daily diary monitoring can be integrated in various treatment programs so that therapists can monitor change processes and use this as input to tailor their therapeutic approach to the needs of the individual. Monitoring live-data thus allows therapists to gain deeper knowledge on the client's behavioural patterns and can facilitate increased self-knowledge for clients themselves.

Focus on personalised care and individual behavioural change for improving mental health in Intellectual Disability

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Keywords Personalised care, momentary assessment, MID-BIF, SPID, challenging behaviour

Background In the last decade, the focus in mental health care shifted towards more personalised care (i.e., treatment based on client characteristics) and (prediction) of individual behavioural change. This symposium aims at presenting methods for personalised care and individual change implemented in facilities for mental health care for people with intellectual disability.

Methods Our methods focus on momentary assessments with daily diary monitoring and physiological stress measures in single case research designs. Daily diary monitoring of clients is used to gain inside into the course of substance use and self-harming and suicidal behaviour in individuals with Mild Intellectual Disabilities or Borderline Intellectual Functioning (MID- BIF) over time. This method also provides opportunities to attune treatment to client needs. In addition, physiological stress measures of clients and caregivers preceding incidents of challenging behaviour in persons with severe to profound intellectual disabilities (SPID) will be presented.

Results/Conclusions Results of several studies in individuals with MID-BIF or SPID and challenging behaviour will be presented and implications for research and mental healthcare will be discussed.

From Science to Practise The focus on personalized care and individual behavioural change is promising for individuals with intellectual disabilities as it helps increasing our understanding of challenging behaviour and it provides opportunities for improving mental health care.

Symposia fifteen (SoS-15 E/OS)

Topic: Models of Care and Support

Resilience in the face of adversity: How people with intellectual disabilities deal with challenging times.

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Keywords Resilience, Adversity, Qualitative research.

Background People with intellectual disabilities are at an increased risk of experiencing adversity throughout the entire lifespan. However little is known about how people with intellectual disabilities are able to manage adversity successfully. The process of effectively negotiating, adapting to or managing significant sources of stress and trauma is called resilience. The current research project aims at studying resilience in people with intellectual disabilities to better understand and promote the process of resilience in people with intellectual disabilities

Methods To fit the strengths and difficulties of people with intellectual disabilities research methods such as 'guided photovoice' were used. A total of 12 guided photovoice interviews will be conducted with people with intellectual disabilities, also 12 interviews will be conducted with a person from the social network of the person with intellectual disabilities.

Results/Aims Various themes will be identified with regard to resilience in people with intellectual disabilities. Also the different perspectives of the person with intellectual disabilities and the person from the support network will be analysed.

Conclusions The concept of (enhancing) resilience in people with intellectual disabilities is a relatively new concept in care. The current studies provide a first insight in resources of resilience in people with intellectual disabilities. These findings can be used to adapt policies and interventions leading to more efficient and effective practice, thus increasing the quality of life in people with intellectual disabilities.

From Science to Practise Professionals have an important role in supporting people with intellectual disabilities in recognizing their resources of resilience and finding ways to expand these resources. Instead of solely focusing on risks and problems resilience offers a holistic view on people with intellectual disabilities as whole persons with their own unique characteristics, leading to the empowerment of people with intellectual disabilities.

Perspectives on burdens, strengths and desires of children with neurodevelopmental disorders in residential care.

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Keywords Children, intellectual disabilities, families, perspectives, visual

Background In the new era of healthcare, a shift from traditional disease-focused care to patient-centred care takes place. Neurodevelopmental disorders, including intellectual disabilities, are still often viewed through the lens of dysfunctions, rather than diversity and strengths. To support one's recovery it is important to focus on strengths, resources, hope and resilience instead of mainly on deficits, pathologies, risks and negative emotions. In the current study a visual and tactile method with colourful building blocks (The Yucel method) was used to explore strengths, burdens and desires of the child and the family.

Methods Nine children, their parents and the involved professionals participated in this qualitative study. All informants were asked to build the strengths, burdens, and desires of the child and family.

Results/Aims Different themes related to the child's and family's strengths, burdens, and desires emerged. The perspectives differed from each other on the level of concreteness, scope, timing and narrative.

Conclusions The results emphasize the importance of professional awareness of different unique perspectives of all involved. Meeting personal perspectives is central to motivation for help, development, wellbeing and recovery. The Yucel method can invite children and their families to share their story and create an overview of their strengths, burdens and desires for themselves and the professionals involved.

From Science to Practise This study emphasizes the importance of centralizing the story and perspectives of children and their families in offering sustainable youth care.

From vulnerability to resilience: Visualising strengths in people with intellectual disabilities.

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Keywords Qualitative Research, Strengths, Resilience, Access to Care.

Background Up until now, practitioners and policymakers often view intellectual disabilities through the lens of dysfunctions, vulnerabilities, and risks. In opposition to such a disease-based approach, this symposium aims to show how a focus on the strengths, desires and personal experiences of people with intellectual disabilities can contribute to healthcare and research practices. First, the results of a study on the dynamic process of resilience in people with intellectual disabilities and their social network is presented. Second, a study is presented in which a visual and tactile method (Yucel) is used to identify experienced strengths, burdens and desires of children with intellectual disabilities and their families. Finally, a visual ethnographic study is presented that reflects on strengths and desires as a methodological starting point in collaborations between academic researchers and people with intellectual disabilities.

Methods Different studies were conducted using qualitative research methods in people with intellectual disabilities. The presented studies all used visual research methods to gain insight into the experiences and perspectives of the participants.

Results/Aims This symposium shows how centralizing and reinforcing strengths in people with intellectual disabilities and their network contribute to both practices of care and academic research.

Conclusions The presenters will discuss ethical dilemmas in the applicability of these results. Furthermore, suggestions are made for policy on how to better accommodate both care- and research practices to the heterogeneous population of people with intellectual disabilities to ultimately strengthen the process of resilience instead of undermining it.

From Science to Practise Current results and conclusions can be used to gain a better understanding of how strengths, desires, experiences and the perspective of people with intellectual disabilities can improve the quality of both care and academic research practices.

Crippled collaborations: Disability as a methodological starting point in academic research.

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Keywords Collaboration, Crip methodology, Visual Anthropology

Background Collaborative approaches have become increasingly emphasized within disability studies. Following the premise of “nothing about us, without us” [1], participatory, or inclusive, approaches strive to put the experiential expertise of participants with intellectual disabilities at the centre of research activities. At the same time, academic standards of what it means to produce knowledge remain to cause trouble in the practice of collaborative disability research. Considering the intellectual and discursive nature of research practices, demands of competency and skill inherently exclude possibilities of collaboration with people with ID. Thinking about how to solve this tension, this study centres around the question of how to collaborate with people with ID in a way that invites their ideas, dreams and ways of knowing into an academic project.

[1] (Charlton, 1998)

Methods This study was conducted using ethnographic, visual and collaborative research methods. Building on the ideas of Crip methodology, this study centres around the coproduction science-fiction film by an artist and aspiring filmmaker with intellectual disabilities and a PhD researcher in medical anthropology.

Results/Aims This study shows how “cripped” collaborations can challenge the notion of what can count as knowledge, and enables researchers to achieve a non-compliant form of knowledge making that embraces people with intellectual disabilities as knowers, makers and activists.

Conclusions Collaborative research with people with intellectual disabilities is not about efforts of inclusion. Instead, it is our methodologies that need to be altered. This study stresses that disability should not be viewed as something that needs to be compensated, but takes disability as a methodological starting point.

From Science to Practise The conclusions can be used to improve collaboration practices in disability studies. Furthermore, the visual products generated through this collaboration can disseminate results to a wide audience.

Symposia sixteen (SoS-2 E/OS)

Topic: Child and Adolescent

Social and non-social influence on social judgments in adolescents with intellectual disability

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Keywords Adolescents, Intellectual disability, Social judgments, Outer directedness, Peer influence

Background Social judgment making about peers defines who adolescents want to spend time with, listen to, and distinguish from. This process therefore can have important implications for individual development. During social judgment making, adolescents with intellectual disabilities are often exposed to non-social and social influences. Due to their cognitive preconditions and limited adaptive skills, adolescents with intellectual disability may show an increased susceptibility to such influences. This study examined the extent of susceptibility to irrelevant non-social cues and social influences from anonymous peers in social judgment making.

Methods Computer-based experimental tasks were developed to examine the susceptibility to non-social and social influences during social judgment making in adolescents with intellectual disability ($n = 34$, $M = 14.89$ years, $SD = 1.38$), chronological-age matched adolescents without intellectual disability ($n = 34$, $M = 14.68$ years, $SD = 1.16$), and mental-age matched children without intellectual disability ($n = 34$, $M = 7.88$ years, $SD = .62$).

Results During social judgment making, adolescents with intellectual disability were more oriented towards non-social ($p < .001$) and social influences ($p < .05$) than adolescents without intellectual disability. No differences were found in susceptibility to non-social ($p = .594$) and social influences ($p = .153$) compared to children without intellectual disability.

Conclusions In social judgment situations, adolescents with intellectual disability show an increased tendency to orient towards irrelevant non-social stimuli and towards opinions of peers.

From Science to Practise Increased susceptibility to non-social and social influences during social judgment making may have both positive and negative consequences for adolescents with intellectual disability. This opens perspectives for planning preventive measures in practice.

Peer-influence in persons with intellectual disability: From science to practice

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Keywords Peer-influence, Childhood, Adolescence, Peer-relations, Special Education

Background Children and adolescents with intellectual disability often experience difficulty in social situations. In this symposium we will focus on

susceptibility to social influence in children and adolescents with intellectual disability.

Methods The three studies in this symposium have respectively investigated how social contact influences language development, how peers influence each other's autistic behaviours and the role of social and non-social influences in social judgement making. The final presentation will integrate the findings and discuss practical implications.

Results/Aims The aim of this symposium is to discuss susceptibility to social influence in children and adolescents with intellectual disability and to discuss implications for practice. This symposium provides a perspective both from longitudinal studies and experimental research.

Conclusions Overall the presented research shows susceptibility to multiple social influences in children and adolescents with intellectual disability, however not on all types of behaviours. Whereas language skills were shown to improve over time with more social contacts, autistic behaviours did not seem to increase under peer-influence. Moreover, the experimental study on social judgments shows that in addition to social influences, non-social influence also explains individual differences in social judgement making. In the final talk, we will discuss how this susceptibility to social influence may have negative and positive consequences for development in children and adolescents with intellectual disability and how this could be included in treatment programs.

From Science to Practise This symposium illustrates how increased susceptibility to social influence may have both positive and negative consequences for the lives of children and adolescents with intellectual disability.

Peer influence on autistic behaviour development

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Keywords autistic behaviour, peer influence, special needs schools, intellectual disabilities

Background Peer influence research indicates that the behavioural development of individual students can be influenced by the behavioural characteristics of their classmates, for example through processes of social learning (Müller & Zurbriggen, 2016). However, very little is known on peer socialization in students with autism spectrum disorder (ASD). We therefore examined the extent to which the level of autistic behaviour in special needs classrooms influences the development of students' individual autistic behaviour.

Methods We analysed longitudinal data of 330 students (age at T1: M=10.17 years, SD=3.74; girls: 20.6 %) with high levels of autistic behaviour according to the Developmental Behavior Checklist and low levels of adaptive skills according to the Adaptive Behavior Assessment System-3. Participating children and adolescents attended special needs schools for students with intellectual disabilities. Future individual autistic behaviour (T2) was predicted by the T1-mean of all students' autistic behaviour level within a classroom, controlling for T1- individual autistic behaviour and other variables (Kindermann, 2016).

Results/Aims Multilevel analyses indicated no significant effect of the classroom level of autistic behaviour on individual future autistic behaviour. More individual autistic behaviour at T2 was predicted by more individual autistic behaviour and less adaptive skills at T1.

Conclusions Autistic behaviour appears to be relatively less affected by the classmates' levels of autistic behaviour. Instead, students' individual characteristics, such as their adaptive skills, may play a more important role. We will discuss our results in terms of developmental questions related to ASD.

From Science to Practice Less sensitivity to peer influence in ASD may be associated with developmental risks as students can benefit less from positive peer influence. Subsequently, it is important to identify ways to support individuals with ASD in learning from their peers.

Language Skills and Social Contact Among Students with Intellectual Disabilities in Special Needs Schools

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Keywords Language skills, social contact, social interaction, intellectual disability, special needs schools

Background Children and adolescents with intellectual disabilities (ID) often have language difficulties. Guided by interactional theories of language acquisition, this study expected that more social contact with peers positively affects language development for this student group. Conversely, it was also hypothesized that poor language skills predict fewer social contacts with peers, thereby reducing their social inclusion.

Methods To test our hypotheses, we studied a sample of 1,125 students (aged 4 to 19 years) in 16 Swiss special needs schools, on whom data was collected at the beginning and end of a school year. Social contact was measured as the number of peers at school with whom a student has frequent contact,

according to teacher reports. Language skills were measured by teacher ratings of verbal and non-verbal abilities.

Results/Aims Results of a cross-lagged multilevel model indicated that greater numbers of social contacts at the beginning of the school year were related to an increase in both verbal and non-verbal language skills. However, better verbal and non-verbal language skills at the beginning of the school year did not predict more social contacts later on.

Conclusions The findings support the assumption that more social contacts among students in special needs schools are conducive to language development, which might be due to more communication opportunities and positive peer-influence.

From Science to Practise Social contact can be regarded as a necessary precondition for social interaction and positive peer-influence. The study shows how important social contact with peers is for persons with IDD to improve their verbal and non-verbal language skills.

Susceptibility to social influence: a way to promote positive development?

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Keywords *Social influence, treatment, childhood, adolescence, mental health*

Background The presented studies suggest that susceptibility to peer influence can have both positive and negative consequences. This is also supported by the broader literature on peer influence in children and adolescents. To prevent negative effects of social influence it is important to develop interventions that help children and adolescents to resist peer influence. In the context of social learning however, openness to learning from peers could also be a strength, as was shown by the presentation on social learning of language skills.

Methods Results from the previous presentations are integrated and linked to the broader research literature.

Results/Aims The aim of this integration is to discuss what the presented studies and broader literature suggest about including a focus on social influence and social learning in interventions and to provide a model to incorporate peers during interventions.

Conclusions Children and adolescents with intellectual disability are susceptible to social influence from their peers. This can have negative, but also positive consequences. Social learning is an important way to develop new skills.

Incorporation of a social learning perspective during interventions may potentially enhance these interventions

.From Science to Practise During this presentation recommendations are made for including peers during interventions and how to use social learning to strengthen positive development in children and adolescents with intellectual disability.

Symposia seventeen (SoS-17 E/OS)

Topic: Challenging Behaviour

Discontinuation of antipsychotic drugs for challenging behaviour; a survey on prescribers' experiences and opinions

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Keywords challenging behaviour, antipsychotics, discontinuation, survey

Background Antipsychotics are still the most widely long-term prescribed agents for a broad spectrum of challenging behaviours (CB). Since there is only low evidence for the short-term effectiveness of these agents and harmful side-effects are common, guidelines recommend non-pharmaceutical interventions as first choice treatments for CB and to deprescribe antipsychotics.

However, in clinical practice implementation of these recommendations is not obvious. Therefore, among other countries, in the UK and the Netherlands initiatives are launched to stimulate implementation of these recommendations.

Methods A survey, in 2019 developed in the UK as part of their initiative, was translated and adapted to the Dutch healthcare situation and set out in March/April 2021 among psychiatrists, intellectual disability-physicians, nurse-specialists, and GPs employed by intellectual disability-organisations in the Netherlands.

The online survey comprises questions on demographics of responders, their experiences and policies regarding antipsychotics' discontinuation, and facilitators and barriers for implementation of advices regarding deprescribing antipsychotics for CB.

Descriptive statistics are used to calculate frequencies of categories of variables. Results are compared with those of the UK-survey.

Results/Aims To investigate prescribers' experiences and opinions regarding discontinuing antipsychotics for CB in their patients with intellectual disability. Analyses will take place in April/May. Definite results will be presented at the congress.

Conclusions By use of similar study methodologies countries can compare the results, share experiences, and learn from each other in implementing guidelines on antipsychotics' prescription policies. Also, exchanging research projects internationally may promote international research on common research questions.

From Science to Practise Stopping over-medication with antipsychotics will favour mental and physical health of individuals with intellectual disability and CB.

Use of integrative models in the assessment of challenging behaviour in individuals with intellectual disabilities

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Drenthe/Assen/the Netherlands Institution2 University Medical Centre

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Keywords challenging behaviour, integrative approach, theoretical models, implementation

Background Multidisciplinary, integrative assessment of challenging behaviours (CB) in individuals with intellectual disability (ID) is recommended, especially in complex and/or long-lasting cases. Theoretical models, displaying the mutual relationships between the developmental, biological, psychological, contextual, ecological, and chronological factors which determine human functioning, may be helpful in integrative assessments. An adapted version of the American Association Intellectual and Developmental Disabilities (AAIDD) model is used as a base in the Dutch guideline 'Problem behaviour in adults with ID' (2019).

The aim of this study is to investigate which components of the adapted AAIDD model are applied in consultation trajectories for CB and their relationship with outcomes of consultation trajectories.

Methods In a retrospective card review among clients with moderate or severe ID of a Dutch mental healthcare organization specialized in CB, who had started a consultation trajectory in 2016 and were expected to have finished at least in 2020, the application of the Dutch model was explored. Participants' characteristics within the eight components of the model, and characteristics and outcomes of consultation trajectories were explored. Outcome-measures are Quality of Life and perceived severity of CB as assessments of the participant's human functioning.

Results/Aims Records of 112 clients were included. Preliminary results indicate that the contextual component of the Dutch model is applied most often. Definite results on the extent to which the Dutch model is applied and its relationship with improvements in participant's functioning after completing the trajectory will be presented.

From Science to Practise More insight on the effect of implementation of integrative assessment of CB in ID-mental healthcare may favour individual's human functioning.

Challenging behaviour, psychotropic drug prescription and restrictive measures: how do they relate?

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Keywords Challenging behaviour, psychotropic drugs, restrictive measures

Background Challenging behaviour (CB) is frequent in people with intellectual disability (ID). Prescription of psychotropic drugs (PD's) and restrictive measures are often applied in the management of CB. We aimed to study the relationship between the presence and severity of CB, the prescription of PD and the use of restrictive measures in residents with ID.

Methods In this cross-sectional study data of 40 residential facilities of six ID care providing organizations in the Netherlands were used. Data on PD prescriptions and standardized questionnaires were used to assess CB and to record the use of restrictive measures. The relationship between CB, PD prescriptions and the use of restrictive measures has been assessed by means of multilevel analysis.

Results/Aims In this study 251 patients were included. Together they used 416 PD's. Behavioural outcomes and restrictive measures were scored for 213 patients. On unilevel analysis, more severe CB was associated with a higher total use of PD's, the presence of polypsychopharmacology, the use of antipsychotics, antidepressants, anxiolytics/hypnotics and antiepileptics. Results of the multilevel analysis will be presented.

Conclusions Preliminary results show that the use of more and different PD's is associated with more severe CB.

From Science to Practise PD prescription for CB is a kind of restrictive measure, namely chemical restraint. In the relationship between CB, PD prescription and the use of restrictive measures we must consider that chemical restraints and

non-chemical restraints may be communicating vessels. When non-chemical restraints are reduced, increase in or ongoing inappropriate PD use may remain unnoticed. Awareness of the necessity of appropriate PD use in combination with reduction of non-chemical restraints will likely increase the quality of life of individuals with ID.

[Symposia eighteen \(SoS-18 E/OS\)](#)

[Topic: Models of Care and Support](#)

The CCE Approach: Intervening in the Situations of Residents with Severe Challenging Behaviour

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^{1,2,3}Centre for Consultation and Expertise

Keywords Challenging behaviour, intellectual disabilities, holistic perspective, multidisciplinary approach

Background The Centre for Consultation and Expertise is a supplementary service to standard healthcare services in the Netherlands. Individuals in need of long-term and/or intensive care sometimes experience situations in which their quality of life is in danger of becoming seriously compromised. We work with independent experts throughout the Netherlands and Belgium to provide customised advice and support within support service organisations. New ideas and expertise can be derived from this exceptional care service. We share this new knowledge with care professionals in the entire sector.

Methods These studies explore the situations of people whose quality of life and level of care is poor. Using various scientific methods and the experience of our professionals we developed an approach to analyse and intervene in these situations

Results/Aims We analysed our daily practices to gain insight into what factors contributed to the success or failure of a particular approach. The focus of this analysis is holistic, looking at personal factors such as psychological and biological aspects as well as at contextual/environmental factors such as social, physical, and organisational aspects.

Conclusions Using a holistic, multidisciplinary approach to analyse and intervene in situations in which people with intellectual disabilities display challenging behaviour is effective. From science to practice

Results from our studies are practice-based. Our aim is to use new insights from these studies in our daily work (consultations), as well as to disseminate our knowledge to the care sector in general. Our aim is to improve the situations of people with intellectual disabilities to enhance their quality of life

Conclusions Using a holistic, multidisciplinary approach to analyse and intervene in situations in which people with intellectual disabilities display challenging behaviour is effective.

From science to practice Results from our studies are practice-based. Our aim is to use new insights from these studies in our daily work (consultations), as well as to disseminate our knowledge to the care sector in general. Our aim is to improve the situations of people with intellectual disabilities to enhance their quality of life.

The Organisational Environment of Residents with Intellectual Disabilities and Challenging Behaviour

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Centre for Consultation and Expertise

Keywords Organisational environment, intellectual disabilities, challenging behaviour, organisational patterns, ecological theory

Background This research was conducted to study the relationships between the organisational environment and challenging behaviour in residents with intellectual disabilities. Bronfenbrenner's ecology theory was used to explore these relationships.

Methods This study consisted of a mixed-methods design (a scoping review of the literature; interviews with professionals, residents, and their representatives; a questionnaire; focus groups) to explore the extent to which various organisational aspects influence challenging behaviour in residents and whether organisational changes have been made in residential disability services for residents with intellectual disabilities and challenging behaviour.

Results/Aims There are aspects associated with challenging behaviour in residents with intellectual disabilities at all levels of the ecological theory (onto, micro, meso, exo, macro, and chronosystem). Furthermore, organisational changes are made to improve support services, however this can also complicate the management of challenging behaviour in residents with intellectual disabilities.

Conclusions Relevant aspects on all ecological system levels exist. Interventions based on these aspects may decrease or increase the ability by professionals to manage challenging behaviour in residents with intellectual disabilities. A holistic ecological perspective on the prevention and management of challenging behaviour in residents is necessary to improve support services.

From science to practice Using a holistic ecological perspective in the support of people with intellectual disabilities and challenging behaviour can positively

impact their daily lives. There are opportunities to enhance support services at all ecological system levels

Good Practice in Cases of Self-Injurious Behaviour in People with Intellectual Disabilities

Peter Koedoot,

Centre for Consultation and Expertise

Keywords Self-injurious behaviour, psychosocial interventions, good practice, severe intellectual disability, multidisciplinary approach

Background Self-injurious behaviour (SIB) may be the worst challenging behaviour exhibited by people with moderate to profound intellectual disability. Hard to watch, and difficult to prevent because continuous proximity is required to stop a person harming him/herself. Carers may also feel responsible for being unable to prevent it, resulting in overuse of restraints and poor quality of life. The Centre for Consultation and Expertise developed a good practice to deal with serious and persistent SIB. It is a methodical, multidisciplinary approach which stresses the importance of both personal and contextual factors. It is also a multi-theoretical approach in which different theories can be used to analyse SIB and to design interventions.

Methods The good practice is based on our institution's experience, literature, case studies, expert meetings, and a field trial. A second field trial is in progress. The focus of our study will be qualitative.

Results/Aims Our primary aim is to reduce SIB among persons in CCE consultation cases by following good practice. We aim to disseminate this good practice by means of case descriptions, expert interviews, and articles.

Conclusions A good practice to deal with SIB is vital in reducing SIB and improving quality of life. We are confident the second field trial will support this conclusion.

From science to practice Too often, it is assumed that SIB may be part of 'who that person is'. This may result in poor interventions, overuse of restraints, and poor quality of life. Our aim is to provide everyone exhibiting serious and persistent SIB the help they need so they can achieve the best quality of life possible

Using Dialogue to Assess the Quality of Life of a Person with Severe Multiple Disabilities

Anouschka Jansen,

Centre for Consultation and Expertise

Keywords Quality of life, severe multiple disabilities, questionnaire, dialogue guide, multi-perspective approach

Background A lot of people with severe multiple disabilities are unable to express what they think and feel in words. Assessing their quality of life is challenging; therefore the Centre for Consultation and Expertise developed the Revised Quality of Life Questionnaire (RQoLQ). This questionnaire facilitates discussion of all aspects related to the quality of life of a person with severe multiple disabilities. The RQoLQ leads to an intersubjective conclusion via Socratic dialogue. The aim is to systematically identify all the aspects influencing a person's quality of life. An accompanying dialogue poster provides guidance for these sessions.

Methods The RQoLQ is based on our institution's experience, literature, user feedback, and a field trial of the original version. A field trial for the revised questionnaire is in progress.

Results/Aims A constructive dialogue is necessary to arrive at as complete a picture as is possible of the situation of a person with severe multiple disabilities. This approach involves taking into account all factors important in quality of life and making complex care questions visible to provide a starting point for the direction of the desired level of care and support.

Conclusions Some factors can be easily overlooked that negatively impact a person's quality of life. Only by carefully looking at multiple factors during dialogue sessions can insights be achieved to improve quality of life.

From science to practice Assessing the quality of life in people with severe multiple disabilities is a challenge. It is crucial to focus on the process and look for the factors that are most relevant to that person's quality of life.

[Symposia Nineteen \(SoS-19 E/OS\)](#)

[Topic: Challenging Behaviour](#)

Effects of problem behavior on acceptance and rejection of students with intellectual disabilities in special needs schools

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Keywords social acceptance, rejection, problem behavior

Background Individual social status (i.e., social acceptance and rejection) among peers has important implications for students' social and academic development. Acceptance and rejection of students with intellectual disabilities (ID) in special needs schools has been little studied so far and less is known on

factors influencing these students' status. The present study investigated the role of individual problem behavior on the development of social acceptance and rejection in special needs schools. Based on the person-group-similarity- model (Stormshak et al., 1999) the moderating effect of descriptive classroom norms was also examined.

Methods Using questionnaires, school staff at Swiss special needs schools for students with ID provided information on the problem behavior, social status, and background factors of 1125 students with ID (M=11.97 years, SD=3.75; female=31%) at the beginning (T1) and end (T2) of a school year.

Results/Aims More individual problem behavior at the beginning of the school year predicted significantly less individual acceptance and more individual rejection at the end of the school year, controlling for students' initial social status, gender, age, adaptive behavior and classroom descriptive norm at T1. The classroom norm on problem behavior had no moderating effect on the influence of individual problem behavior on social status.

Conclusions Our finding is consistent with results reported for other school contexts where problem behavior has proven to be a risk factor for students' social inclusion. We will discuss our results in terms of their relevance for the support of students with ID.

From Science to Practise Having identified problem behavior as a predictor of social status, this may help professionals to better understand and intervene in situations where students with ID risk social exclusion among their peers in special needs schools.

Training resistance to peer influence in adolescents with mild-to-borderline intellectual disability

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5Leiden University

Keywords mild-to-borderline intellectual disability, training, resistance to peer influence, adolescents, pilot

Background Adolescents with a mild-to-borderline intellectual disability (MBID; $50 < IQ < 85$) often get into trouble due to peers negatively influencing them to make risky decisions. In this presentation, we present our pilot study on a new training aiming to increase resistance to negative peer influence in adolescents with MBID.

Methods The training was adapted from an American protocol (Khemka et al., 2016). We included new aspects such as peer influence videos and role plays with an actor to improve generalization. From April to June 2021, the training will be piloted in a group of 6 adolescents with MBID (13-15 years) at a vocational school. Before and after the training, we will administer self- parent- and teacher-reports about resistance to peer influence, prosocial behavior, peer problems and risk taking, as well as a one-week daily diary on peer influence for adolescents.

Results/Aims We aim to increase resistance to peer influence as well as to decrease risk taking. We explore how training outcomes relate to peer relation indicators such as prosocial behavior and peer problems. In the presentation, we will present the results and our future study plans. Feedback from both scientific and clinical angles is highly appreciated.

Conclusions Based on the pilot results, we adapt our current protocol and instruments.

From Science to Practise As adolescents with MBID often get into trouble due to peer influence, this training has the potential to improve their interactions with peers and to increase social assertiveness.

Is problem behavior development of students with intellectual disability, influenced by their classmates' characteristics?

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Keywords Peer influence, problem behavior, classroom

Background Students with intellectual disabilities (ID) exhibit increased rates of problem behaviors compared to those without ID. Given the evidence of peer influence in typical development, we examined the impact of classmates' characteristics on problem behaviors of students with ID. We expected that the levels of problem behaviors in special needs classrooms will influence individual development of such behaviors.

Methods A longitudinal design with measurements at the beginning and the end of a school year was applied. Staff reported on students' problem behaviors using the Developmental Behavior Checklist. Information on 1125 students with ID (69% boys; age 11.30 years, $SD = 3.75$) attending 16 Swiss special needs schools was collected.

Results/Aims Levels of problem behavior were generally high in the considered special needs settings (i.e., at T1 51.6% and at T2: 49.7% of students had scores above the cutoff indicating clinical relevance). The peer influence hypothesis

was not supported regarding an overall score of problem behaviors. However, exploratory analyses suggested that peers tended to influence individual anxiety, problems in relating socially, and communication disturbances (not disruptive, self-absorbed and other types of problem behaviors). More within- classroom heterogeneity of students' anxiety reduced the effect of classmates on anxious behavior. Development of communication skills benefited from attending classrooms heterogeneous in the levels of communication problems.

Conclusions Our results suggest that peer influence on problem behaviors in special needs schools is not universal but may vary between domains and depend on classroom characteristics.

From Science to Practise For some domains of problem behaviors this study suggests that students with ID may benefit from low mean levels and greater heterogeneity of these behaviors among classmates in special needs schools.

Peer relations and problem behaviors in children and adolescents with intellectual disabilities

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1University of Fribourg, 2University of Amsterdam

Keywords Challenging behaviors, peer relations, peer influence

Background Problem behaviors are relatively frequent in ID and can pose challenges for the concerned children and adolescents and their social environment. A social group of special importance at this age is the peer group. Exhibiting problem behaviors may contribute to a low social status among peers. Also, the behavioral characteristics of the peer group at school may influence the development of individual behavioral problems of students with ID. It would therefore be helpful to have means to help individuals with ID in resisting negative peer influence. We will tackle these issues reporting on findings from three studies.

Methods The studies on social status and peer influence were questionnaire-based and involved longitudinal measurements among 1125 students with ID attending special needs schools. The pilot study evaluating a training of resistance to negative peer influence was conducted in a vocational school.

Results/Aims Our findings show that behavioral problems are frequent at special needs schools for students with ID. In this school setting, exhibiting problem behaviors is associated with less social acceptance and more rejection among peers over time. Some types of behavioral problems are found to be influenced by the levels of these behaviors among the classmates. First insights

on the effects of a peer intervention will show how promising this approach may be to reduce negative peer influence.

Conclusions Results presented suggest that research focusing on the peer context can contribute to a better understanding of challenging behaviors and development of individuals with ID.

From Science to Practise We will discuss our results in terms of their relevance for the practical support of children and adolescents with ID in their surrounding peer context

Symposia twenty (SoS-20 E/OS)

Topic: Emotional Development

Validation and Extensions of the Scale of Emotional Development – Short

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Keywords Emotional development

Background

The Scale of Emotional Development – Short (SED-S, 200 items) measures the level of emotional development (ED) in persons with intellectual disability. The aim of the study was to develop a brief version of the SED-S.

Methods A sample of 447 German adults with intellectual disability was divided in two matched subsamples. The first sample ($n_1 = 224$) was used to develop a brief version of the SED-S with item analysis (proportions, Chi-square test, Spearman-correlation, part-whole corrected selectivity). The brief version was validated in the second sample ($n_2 = 223$), an additional sample of children with intellectual disability ($n_3 = 112$) and a Dutch sample of adults with intellectual disability ($n_4 = 96$).

Results/Aims Each item set ranged between Cronbach's $\alpha = .835 - .924$.

Weighted kappa resulted in $\kappa_w = .743$ ($p < .001$, $SE(\kappa) = .029$, $KI\ 95\% = [.690-.802]$) for sample 2. The overall agreement of the SED-S-stage of the brief version with the SED-S as reference was $PO = .7$. In sample 3, weighted kappa was $\kappa_w = .787$ ($p < .001$, $SE(\kappa) = .039$, $KI\ 95\% = [.711-.863]$) and the overall agreement $PO = .759$, in sample 4, weighted kappa was $\kappa_w = .587$ ($p < .001$, $SE(\kappa) = .059$, $KI\ 95\% = [.471-.703]$) with an overall agreement of $PO = .604$.

Conclusions Based on single item analysis, a brief version of the SED-S (80 items) was developed. However, due to difficulties in differentiation SED-2 and to some extent SED-5 from adjacent SED-S-stages, a rephrasing of the current item set is the prerequisite to improve the validity of a brief version of the SED-S.

From Science to Practise Item analysis demonstrated some items of the SED-S need a rephrasing.

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Validation and Extensions of the Scale of Emotional Development – Short 1

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Keywords Emotional Development

Background SED-S is a standardised diagnostic instrument for assessing emotional development (ED) in persons with intellectual disability. SED-S defines five ED stages and covers emotional reference age groups up to 12 years in eight domains. Five items/domain describe behaviours typical for each stage. The aim of this study is to extend the SED-S for a further stage, covering the reference ages from 13-17 years.

Methods Experts in developmental psychology developed 56 items (7/domain) describing typical behaviours for emotional reference ages from 13-17 years in English, German and Dutch. Twenty-eight independent experts assessed content validity and observability of these items on a Likert scale (0 = “good” to 3 = “unacceptable”) and gave feedback in form of free-text comments. Subsequently, the 2 items/domain with the lowest content validity and observability ratings were excluded. The remaining 5 items/domain were selected to define the behaviours typical for phase 6.

Results/Aims The experts’ ratings were rated as “good” with results ranging from 0.06 to 0.78 for content validity and 0.06 to 1.78 for observability. After exclusion of the 2 items/domain, the final 5 items/domain were selected to define the behaviours typical for persons with an emotional reference age of 13-17 years. The free-text comments were assigned to categories to adapt the scale in a second step.

Conclusions A further SED-S stage “Social Individuation” will enable differentiation in upper ED range and give insights into the needs and motivations of higher functioning persons. Yet, further research should evaluate the items’ psychometric characteristics.

From Science to Practise Extending the SED-S will help clinicians and caregivers to better understand persons with higher ED levels and target interventions more effectively.

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Validation and Extensions of the Scale of Emotional Development – Short

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Keywords Emotional Development

Background Considering the increased vulnerability for mental health issues (e.g., Cooper et al., 2007) and limited communicative abilities of persons with an intellectual disability, standardized instruments to better understand their psychological needs are required. The Scale of Emotional Development – Short (SED-S; Sappok et al., 2016), an informant-based structured interview, assesses the level of emotional development (ED) of persons with intellectual disability on eight domains across five stages with reference ages from 0-12 years. The aim of this study was to test the applicability and validity of the SED-S.

Methods Eighty-three mentally healthy adults with intellectual disability were assessed with the SED-S. Confirmatory factor analysis (CFA) was applied testing a one-factor model of the eight domains of the SED-S. Reliability was estimated with Cronbach's alpha. Correlations between the SED-S and severity of intellectual disability and biological age were computed to examine the concurrent and discriminative validity of the scale.

Results/Aims Using the SED-S, it was possible to assign a level of ED to all participants on domain and scale level, demonstrating the scale's applicability. The CFA supported a one-factor solution of the SED-S. Reliability was high (Cronbach's alpha = .92). The SED-S correlated significantly with the severity of intellectual disability ($\rho = -0.753$, $p < 0.001$), but not with biological age ($\rho = .068$, $p = .539$). No significant gender differences could be detected ($\chi^2 = 0.658$, $df = 1$, $p = 0.417$).

Conclusions The SED-S is applicable, valid, and reliable for assessing ED in mentally healthy adults with intellectual disability.

From Science to Practise The SED-S can be applied in adults with intellectual disability. This may support caregivers to acknowledge the emotional needs and provide appropriate treatment and care.

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Validation and Extensions of the Scale of Emotional Development – Short

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Keywords Emotional Development

Background Intellectual development disorders (IDD) are often accompanied by delays in emotional development, which may result in challenging behaviour. To provide better treatment and more understanding of the needs of persons with IDD, a valid assessment of socio-emotional brain functions is necessary. We therefore aim to study the validity of the Scale of Emotional Development – Short (SED-S), an instrument widely used in various languages. The SED-S consists of eight domains describing emotional development resulting in five levels of development.

Methods The SED-S was applied in a sample of 724 adults in five study sites in Belgium, the Netherlands and Germany. Using a confirmatory factor analysis (CFA), the factor structure of the SED-S was examined. A one-factor model was tested within the whole dataset and in different subgroups to further assess the effects of gender, mental disorders, autism spectrum disorders (ASD) and the severity of ID on the model fit.

Results/Aims The one-factor model of emotional development was suitable to explain the eight domains of the SED-S. The factor analysis provided a good model fit, with CFI = .999, TLI = .999, RSMEA (90% CI) = .032 (.013-.05) and SRMR = .022. The construct was valid for all subgroups.

Conclusions The SED-S model of eight domains is valid for assessing the level of emotional development in persons with various levels of disability. The Scale is applicable in males, females, persons with and without ASD and/or mental disorders across all age groups.

From Science to Practise This study validated the factor structure of the SED-S, an assessment instrument to measure socio-emotional brain functions

.Disclosures Tanja Sappok receives royalties of Hogrefe and Kohlhammer for the publication of the SED- S and other book projects.

Validation and Extensions of the Scale of Emotional Development – Short

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Keywords Emotional development

Background Taking a developmental perspective can help to better understand the needs and behaviours of persons with an intellectual disability. The Scale of

Emotional Development - Short (SED-S) assesses the level of emotional development (ED) in persons with intellectual disability on eight domains across five stages (reference age: 0-12 years). The current studies aim to assess the scale's psychometric properties.

Methods The construct validity of the SED-S was examined using confirmatory factor analysis to test a one-factor model of ED in different subsamples. The association of the SED-S with the severity of intellectual disability and biological age was examined. An item analysis was conducted to develop a brief version of the SED-S. New items were constructed and tested for validity and observability to expand the emotional reference ages up to 18 years.

Results/Aims The one-factor solution of the SED-S was supported in all subsamples. The SED-S correlated significantly with severity of intellectual disability, but not with age. The items of the brief version were reliable and valid in general but showed some lack of discrimination for SED-S-stage 2 and 5 to adjacent stages. Observable and valid items could be selected to form a basis for SED-S- stage 6.

Conclusions The SED-S is a unidimensional measure of ED and applicable in adults with intellectual disability. In the brief version, most items discriminated well between the SED-S-stages, while some should be rephrased. The items developed for stage six allow for a more pronounced differentiation of ED, particularly in high-functioning persons.

From Science to Practise The SED-S can be applied in clinical and non-clinical settings to assess ED, helping practitioners consider emotional needs and potentially alleviate difficult person-environment interactions.

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Solicited Symposia German on-site

Symposia one (SoS-24 G/OS)

Topic: Health Literacy, Health Promotion, Health Education

Participatory development of a health education program for people with intellectual disability.

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Keywords health education, health promotion, participatory health research, inclusive education, intellectual disability

Background A central question in the development of health education programs is to what extent the participants accept a program. Studies show, that health education programs are more successful if they are developed by

professionals together with the target group. So far, few examples exist of a participatory approach for people with intellectual disability.

Methods To develop a health education program, a group of people with and without disabilities worked together over a period of two years. This team consisted of seven persons from a sheltered workshop and four persons from the university. The university served as an inclusive place of work and study. The collaboration in the team was guided by the approach of participatory health research.

Results/Aims Four health-promoting seminars were jointly developed at the university. The seminars were tested in a sheltered workshop and evaluated for their applicability and comprehensibility. The seminars focus on topics such as heart health, beverages and nutrition, and relaxation. They also include aspects of sustainability and environmental protection - which are closely connected to the health topics.

Conclusions The life experience and knowledge of the participants with intellectual disability foster the acceptance of this health education program. The process of developing the seminars was complex and time-consuming. However, the program has been shown to be motivating and comprehensive.

From Science to Practise The cooperating sheltered workshop has integrated the four seminars into its own educational program and is offering the program to further disability organisations. The curricula of the seminars have been published for dissemination.

Participatory approaches to health promotion with people with intellectual disability

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Keywords Health Literacy, Health Promotion, Health Education, Participatory Approach

Background Health promotion programs find greater acceptance among participants if their experiences and needs are included in the development process. Successful collaboration and participation in those programs require concepts and strategies that take into account the special resources and needs of people with intellectual disability. Theory and practice of participatory approaches in health promotion are still in the early stages of developing good practices. To expand this knowledge, three projects using a participatory study design are presented.

Methods Three good practice examples from different areas are presented:

Project GESUND!: Participatory development of a health education program for people with intellectual disability. Challenges and opportunities.

Toolbox for strengthening health literacy in the area of substance use by and for people with intellectual disabilities (SKoL: Substance Use Literacy TooLbox).

“With Enthusiasm and Energy throughout the Day“: Participatory development of an intervention to promote a physical activity lifestyle addressing physical activity related competencies and health literacy.

Results/Aims Although the focus of the three projects was different and participants’ needs were very heterogeneous, all projects used a participatory approach successfully. Thus, methods, concepts and strategies had to be adapted to the resources and needs of the participants and requires a high level of professionalism to act.

Conclusions A participatory approach in research and health promotion programs with people with intellectual disability is rewarding and has a great benefit to strengthen health, health literacy and self-efficacy among groups.

From Science to Practise To apply participation and participatory research in health promotion programs for people with intellectual disability is still in progress, offers benefits to the settings and users.

Health literacy in the field of substance use by and for people with intellectual disabilities (SKoL-Toolbox)

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Keywords substance use, participatory approach, intellectual disability, gamification, prevention

Background The attention for substance use (SU) among (young) adults with mild to borderline intellectual disability (MBID) has currently been growing. However, screening instruments, measures to strengthen health literacy as well as programs to prevent SU are still scarce for the German speaking countries.

Methods SKoL is based on the participatory step-by-step approach of the Intervention Mapping Approach (IMA). The toolbox is planned, developed and implemented in facilities for people with disabilities (sheltered workshops and residential groups). According to a needs- assessment, the toolbox consists of analogue, digital and gamified elements (e. g. role play, Photovoice, video-tutorials, vignettes). Lastly, a practical guide and a transfer concept will be

provided to disseminate the tools to other target groups and settings (e. g. schools).

Results/Aims SKoL aims at

1. developing tools to strengthen health literacy, the decision-making and skills in the field of SU among young adults with MBID based on existing materials, concepts and programs, and
2. training staff in the area of SU among people with MBID.

Conclusions Due to the growing inclusion and self-determined lifestyle of young adults with MBID, SKoL addresses the availability, accessibility and acceptance of target group-adequate tools.

From Science to Practise The toolbox will contain target-group specific formats by and for people with MBID in order to initiate a conscious handling of SU.

“With Enthusiasm and Energy”: Promoting physical activity in people with intellectual disabilities”

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1,2,3Fachhochschule Bielefeld

Keywords: intellectual disabilities, participatory approach, physical activity, health promotion

Background: People with intellectual disabilities show significantly lower levels of physical activity than the general population, with all its consequences for health. Interventions that take into account their specific resources are rare. Mostly the perspective of People with intellectual disabilities is not taken into account, although intrinsic motivation is highly relevant. A project is presented, that used a participatory approach to develop an intervention to promote a physically active lifestyle.

Methods: For collaboration with potential users an expert board was established comprising of two PWID. All project steps were discussed here. For research related activities a research group was founded with six People with intellectual disabilities To take in the staff perspective, the project coordinator of the cooperation partner took part in both groups.

Results: In collaboration with these groups an intervention was developed taking into account everyday life conditions and existing health literacy to promote a physically active lifestyle in consideration of self-determination/-efficacy. Important project components such as the intervention title were developed by the expert board. The research group took part in developing target group oriented questionnaires for assessing the needs of People with intellectual disabilities in relation to an intervention concept. Exercises were discussed and adapted before including them into the intervention. The entire

intervention, focusing on possible barriers to personal motivation, was discussed in both mentioned groups. By using this approach, a supportive concept for behaviour change was successfully implemented.

Conclusions: The participatory approach resulted in an encouraging intervention, that was successfully tested in practice. Therefore, a promising way to promote physical activity could be to explore and build upon existing health literacy.

From Science to Practise: Empowerment was achieved by enabling the target group to bring in their own experiences and competencies and by integration of their living environment.

[Symposia two \(SoS-25 G/OS\)](#)

[Topic: Trauma and Abuse](#)

Treatment and educational support for people with intellectual disabilities and trauma-related disorders

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Keywords Intellectual Disability, Trauma, NET (Narrative Exposure Therapy), Imaginary Rescripting, educational support

Background Although the likelihood of experiencing traumatic events is significantly higher in people with intellectual disabilities than in the general population, the subject of “trauma-related disorders in people with intellectual disabilities” is still a rare research topic today. There are only a few adapted diagnostic tools and adapted trauma therapy methods. The level of knowledge on this topic can be described as low.

Methods In 2 parts of the symposium, the therapy with NET (Narrative Exposure Therapy) is presented, in 2 other parts the trauma therapeutic work also with complex trauma and the important close cooperation with the care givers. Adaptations of the NET, but also of trauma diagnostics, are also presented.

Results/Aims NET is applicable and effective, but there are also other possibilities of trauma therapy, also beyond stabilization. Close cooperation between pedagogic and therapy is necessary and it must be shaped by trauma pedagogical principles.

Conclusions Further research is needed. The interface between trauma therapy and intellectual disability urgently needs to be enlarged and cooperation between these areas improved.

From Science to Practise Trauma therapy offers must also be available and accessible for people with disabilities. Since many traumatized people show

behavioural problems, everyone involved in the care system should have basic knowledge in the area of "impairment and disability", including how to identify possible trauma symptoms.

Severe developmental trauma and the educational and therapeutic work using the BEP-KI-k

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Keywords BEP-KI-k (well-being-oriented development profile for normally gifted children and people with intellectual disabilities - short), Developmental Trauma, educational work, EfB (Entwicklungsfreundliche Beziehung)

Background Traumatization in childhood significantly increase existing impairments, but are not always easy to diagnose, especially when the language level is significantly above the level of socio- emotional development. As a result, the educational and therapeutic support needs are incorrectly assessed and the trauma symptoms are attributed to the disability. Diagnostic overshadowing occurs.

Methods In a case study of a thirty-year-old-man with intellectual disability and sexually assaulting and self-harming behaviour the problems of the educational and therapeutic setting are reported. Because of problems in the care setting, he lost his place to live. The problems were attributed to the impairment and the massive early childhood trauma and the resulting dissociation in everyday life were overlooked. Only by using BEP-KI-k based on the EfB (development-friendly relationship according to B. Senkel and U. Luxen) it was possible to find the right starting points for educational and trauma therapeutic interventions.

Results/Aims Only through the differentiated classification of the socio-emotional level of development and resulting indications for everyday life it was possible, after years of unsuccessful effort, to make changes in the client's life. In a control classification after 1.5 years, these educational and therapeutic intervention are already noticeable in the development profile. Challenging behaviour decreased massively.

Conclusions Trauma knowledge is necessary, interventions in everyday life must take into account the differentiated level of development and a close cooperation between pedagogical and psychotherapeutic work is helpful.

Narrative exposure therapy in people with intellectual or psychol. disability- results of a study

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Keywords NET (Narrative Exposure Therapy), plain language, KERF, PTSS-10, control group

Background Trauma and impairment is an area that receives little attention from the professional world, although traumatization rates are high. There is hardly any research and no published studies with a comparison group. So far there are rarely adapted trauma-therapy methods.

Methods In an intervention study (n=15, 10 with intellectual disability) with a randomized control group it was investigated whether NET in an with plain language adapted form can be carried out and if there are significant improvements in trauma symptoms. The clientele is characterized by challenging behaviour and many years of hospitalization. The trauma symptoms were measured with PTSS-10, the traumatic life experiences recorded with the KERF.

Results/Aims In KERF, supplemented with the described events in the NET, almost all clients showed polyvictimization. The NET was applicable to all clients. After the NET, the clients showed highly significant changes in trauma symptoms reported in PTSS-10, not in the waiting group. The effect size is very high with a $d = 1.7$.

Conclusions NET is not only applicable, but also highly effective for this clientele. The high rates of trauma symptoms and the reported polyvictimization, demonstrate the need for trauma- therapy for traumatized people with disabilities. KERF and PTSS-10 are suitable tools for diagnosis.

From Science to Practise Trauma knowledge should be available and more specially adapted therapy methods should be developed.

Narrative and Imaginary Methods in the Treatment of Childhood Abuse Trauma – a Case Study

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Keywords Trauma, PTBS, Narrative Exposure Therapy, Imaginary Rescripting, Psychotherapy

Background People with intellectual development disorder (IDD) are at a higher risk of experiencing both physical and sexual violence. Furthermore, they often have fewer protective factors which leads to high prevalence of posttraumatic stress disorders and other trauma-related mental health problems. There are only few approaches of psychotherapy for this target group and few services that actually offer these services.

Methods I present a case study about a woman with mild IDD and multiple childhood trauma. We used a combination of narrative elements with imaginary rescripting and other imaginary methods to activate resources, reconstruct and integrate traumatic experiences in the biographical memory, reduce hyperarousal and challenge feelings of guilt. The lessons derived from this case study were used for the treatment of further patients, also with moderate IDD.

Results/Aims The combination of Narrative Exposure Therapy with imaginary techniques proved to be both effective and gentle enough to prevent dropout. It combined the necessary confrontation and integration of traumatic memories with resource activation and led to a reduction of PTBS-symptoms and an increase in social participation and activity. The psychotherapy was supported by individual social services with whom important steps were coordinated. This helped to create a safe therapeutic space for the patient.

Conclusions Psychotherapy for people with IDD and PTDS is possible, effective and safe. The combination of narrative and imaginary elements can be recommended. Other services must be won as supporters of the psychotherapy and play an important role in the acceptance and compliance with the therapeutic progress

From Science to Practise Since many traumatized people show behavioural problems, everyone involved in the care system should have basic knowledge in the area of "impairment and disability", including how to identify possible trauma symptoms.

[Symposia three \(SoS-26 G/OS\)](#)

[Topic: Physical Health / Health Inequalities](#)

The differential diagnosis of diarrhoea in adult patients with intellectual disabilities

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Keywords recommendations, diarrhoea

Background There are only limited data from prospective and interventional studies about medical care of patients with intellectual disability. Guidelines like the recently published down syndrome guideline or the Canadian consensus guidelines about Primary care of adults with intellectual and developmental disabilities might help to improve the medical support for these patients. But as evidence based data are scarce otherwise, expert recommendations might be useful.

Methods review of literature, expert panel

Results/Aims Gastrointestinal symptoms like diarrhoea are a frequent cause for medical consultations of patients with developmental disorders and physical impairment. We developed a short guideline for the evaluation of this medical problem with special consideration of this group of patients. The differential diagnosis of diarrhoea differs from the average population in some points and requires a careful approach including medical history, clinical examination and further investigations.

Conclusions Expert recommendations based on literature as well as on observations might support the medical management of patients with intellectual disability.

From Science to Practise Our recommendations, which are based on available evidence and experiential knowledge of experts, are intended to improve the treatment of people with intellectual disabilities and to help avoid both underdiagnosis and overdiagnosis.

Recommendations of the DGMGB for the medical care of patients with intellectual disability

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Keywords recommendations, obesity, diarrhea, pain, deterioration of motor functions

Background There are only limited data from prospective and interventional studies about medical care of patients with intellectual disability. Guidelines like the recently published down syndrome guideline or the Canadian consensus guidelines about Primary care of adults with intellectual and developmental disabilities might help to improve the medical support for these patients. But as evidence based data are scarce otherwise, expert recommendations might be useful.

Methods review of literature, expert panel

Results/Aims With regard of the literature we present expert recommendations of the DGMGB (German medical society for patients with intellectual disability) dealing with the medical problems of patients with intellectual disability. We focus on the prevention, diagnostic demands and treatment of obesity and report clinical pathways for the differential diagnosis of diarrhoea, abdominal pain and the deterioration of motor functions in patients with intellectual disability. Further recommendations for other medical problems are under development.

Conclusions Expert recommendations based on literature as well as on observations might support the medical management of patients with intellectual disability as long as evidence based data are scarce.

From Science to Practise Our recommendations, which are based on available evidence and experiential knowledge of experts, are intended to improve the treatment of people with intellectual disabilities and to help avoid both underdiagnosis and overdiagnosis.

Pain in adults with developmental disorders – From symptom to diagnosis

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Keywords recommendations, pain

Background There are only limited data from prospective and interventional studies about medical care of patients with intellectual disability. Guidelines like the recently published down syndrome guideline or the Canadian consensus guidelines about Primary care of adults with intellectual and developmental disabilities might help to improve the medical support for these patients. But as evidence based data are scarce otherwise, expert recommendations might be useful.

Methods review of literature, expert panel

Results/Aims In particular, people with significant intellectual impairment have great difficulty expressing pain. In many cases this leads to uncertainty and delayed diagnoses with sometimes serious consequences for those affected. Sudden changes in behaviour should prompt a thorough evaluation of these patients. Proposals for systematic somatic diagnostics are presented, taking into account the common causes of pain in this patient group.

Conclusions Expert recommendations based on literature as well as on observations might support the medical management of patients with intellectual disability.

From Science to Practise Our recommendations, which are based on available evidence and experiential knowledge of experts, are intended to improve the treatment of people with intellectual disabilities and to help avoid both underdiagnosis and overdiagnosis.

Functional deterioration in adults with cerebral palsies – the differential diagnosis

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Keywords recommendations, deterioration of motor functions, cerebral palsy

Background There are only limited data from prospective and interventional studies about medical care of patients with intellectual disability. Guidelines like the recently published down syndrome guideline or the Canadian consensus guidelines about Primary care of adults with intellectual and developmental disabilities might help to improve the medical support for these patients. But as evidence based data are scarce otherwise, expert recommendations might be useful.

Methods review of literature, expert panel

Results/Aims Functional deterioration is frequently noted in adult patients with cerebral palsy (CP). Although factors intrinsic to CP may contribute in a large part to the decline in motor functioning, other causes have to be considered in an individual patient. This contribution is aimed to survey possible frequent and rare causes of progressive functional impairment of adults with CP. As CP and some neurodegenerative and neurometabolic disorders share main clinical features, it is of outstanding importance to bear in mind a wide spectrum of conditions that may have been misdiagnosed as CP during infancy.

Conclusions Expert recommendations based on literature as well as on observations might support the medical management of patients with intellectual disability.

From Science to Practise Our recommendations, which are based on available evidence and experiential knowledge of experts, are intended to improve the treatment of people with intellectual disabilities and to help avoid both underdiagnosis and overdiagnosis.

[Roundtables English and German Online](#)

[Topic: Developmental Neuroscience \(RT-5 E/OS\)](#)

The assessment and treatment of ASD and/or attachment disorders in persons with an intellectual disability

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Keywords Autism Spectrum Disorder (ASD), attachment disorder, Intellectual Disability, attachment therapy, Neurobiology

Background In practice it sometimes is hard to differentiate between behavior related to autism spectrum disorders (ASD) and attachment disorder (RAD/DSED). Giltaij et al. (2016) reported that in their study there

were children with a mild intellectual disability with ASD and RAD/DSED, but also children with ASD without RAD/DSED. However, for children with an intellectual disability and ASD the prevalence for RAD/DSED is higher than for children without ASD.

Methods First case studies will be presented. Then the theoretical aspects, assessment and treatment of ASD and RAD/DSED will be presented very briefly. The session will be rounded off with the presentation of the new book on the Integrative Therapy for Attachment and Behavior.

Results/Aims

Discuss:

- 1) The ways in which to distinguish between ASD and RAD/DSED.
- 2) Whether there is a comparable behavioural profile in ASD and RAD/ DSED in terms of reduced connectivity in the brain and between diverse neural centres in the brain (Bentzen & Hart, 2015; Emerson et al. 2017).
- 3) The therapeutic approaches that are recommended for ASD and/or for RAD/DSED.

Conclusions We will discuss the opportunities to collaborate for future studies concerning ASD, RAD/DSED and neurobiologically oriented attachment research.

From Science to Practise Practical examples of the Integrative Therapy for Attachment and Behaviour are presented in the new book on attachment therapy for persons with severe to moderate ID. The differences and commonalities between ASD and RAD/DSED behavior, and the assessment and treatment possibilities are discussed, and ideas are shared for future collaborations.

[Topic: Mental Disorders \(RT-8 G/OS\)](#)

The effects of attachment disorders during childhood of people with intellectual disabilities

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Background Attachment disorders can lead to negative neurobiological development in children with intellectual disabilities and significantly increase the possibility of developing mental disorders.

Methods Behavioral Therapy, Cognitive behavioral Therapy / EMDR / Comprehensive Ressource

Model (CRM) by Lisa Schwarz, M.E. / EDxTM by PhD Fred Gallo

Results/Aims Decreasing the SUD and integrate negative experiences without further suffering of the patient.

Conclusions Attachment disorders create negative interacting neurobiological “loops” in the brain including negative affects and cognitions. Therefore a safe and protective relationship is essential. Therapeutically we use imaginary “protective people” (e.g. an angel) or “protective animals” as “attachment objects” which in the process become resources for the patients. The “attachment objects” support treatment of negative experiences which occurred in the past and lead to a decreasing degree of stress (SUD). This method allows for an integration of traumatic experiences without overwhelming the patient in the process.

From Science to Practise The use of “attachment objects” allow for a more effective integration of traumatic memories than previously used methods by keeping the perceived traumatic stress on a moderate level.

Keywords attachment disorder, neurobiological results, children with Intellectual disabilities, attachment objects, psychotherapy

[Roundtables Onsite English and German](#)

[Topic: Trauma and Abuse \(RT-4 E/OS\)](#)

Practical Implications from Embedding a Trauma-Informed Approach in response to ‘Transforming Care’

1Robert Ferris-Rogers, 2Peter Langdon, 3Noelle Blackman, 4Wendy Ewins,
1Robert Ferris- Rogers NHS England, 2Warwick University, 3Respond, 4Black Country Healthcare NHS Foundation Trust

Keywords Trauma and abuse

Background NHS in England has an ambitious transformation programme for people with an intellectual disability and/or autism. There are limitations with existing models of care to impact onto the lives of people heavily traumatised by their experiences to live in the least restrictive environment as possible. NHS England in the Midlands have piloted with local systems and Respond the use of a trauma informed approach to enable different outcomes for highly complex and heavily traumatised people. The session will share the practical learning and application of the approach

Methods

The pilot focused upon two key interventions: Training senior leaders, frontline staff and trauma champion training Working intensively with three clients using a trauma informed approach delivered by Respond. The approach had four key phases; pre-transition, active transition, active support in the community, embedding in the community. Evaluation by Warwick University

Results/Aims The approaches demonstrated significant increase in the knowledge base of staff. The outcomes for the individuals worked with in a trauma informed way was significantly improved once a trauma informed lens was applied and has radically changed outcomes for patients e.g. An individual who would have had care delivered in a secure unit is now living in the community due to the difference the approach has made.

Conclusions Knowledge transfer and different approaches radically changes the pathways for people impacted by trauma. The session will share the practical experience of implementation and the wider impacts for providers, commissioners and policy makers.

From Science to Practise Long term change for people with complex trauma has been enabled through a consistent relational approach – attunement, acceptance, containment

Topic: Mental Disorders (RT-2 E/OS)

Mental health & intellectual disabilities; a transdiagnostic approach to improve practice & research

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Keywords mental healthcare; transdiagnostic approach

Background Diagnosing individuals with intellectual disability (ID) is complicated, due to the simultaneous presence of developmental disabilities, somatic problems, and mental health issues. Categorical classification systems, such as the DSM, ICD and even DSM-ID in most cases do not apply well to the ID population. As a result, treatment allocation is difficult since knowledge on proper interventions for such complex phenotypes is lacking.

Apart from affecting clinical practice, problems with description and classification of mental illness hamper scientific research on mental health problems in individuals with ID. Study outcomes are affected significantly by heterogeneity in study populations and treatment allocation plans. As a result, there is lack of evidence-based treatment for specific mental problems, which in turn affects possibilities and choices in clinical practice.

Aims To discuss a transdiagnostic approach of mental health problems in individuals with ID as an alternative for categorical classification systems and learn from experts in other fields of mental health care. Furthermore, we aim to

initiate a European research network on this transdiagnostic approach. We explicitly invite delegates from COST-member -, COST- partner-member -, COST-international-partner - and COST-near-neighbour countries to join our roundtable.

From Science to Practise Going beyond categorical diagnostics may create larger possibilities to account for the wide variety in characteristics and mental symptoms of individuals with ID in mental health research, which in turn will create larger possibilities to provide better tailored mental healthcare. A European COST-research-network will create possibilities to substantiate the evidence of research findings as a base for international guidelines, which will likely improve the quality of mental healthcare for all European citizens who are intellectually disabled.

Topic: Emotional Development (RT-1 E/OS)

An International Manual Emotional Development and Intellectual Disability

1Jac de Bruijn 2Ajolanda Vonk, 3 Ad van den Broek, 4Brian Twint.

1YouCare, 2Oro/Lore, 3Fortior Training, 4Cordaan.

Keywords Emotional Development, Intellectual Disability, International Publication,

Background From different perspectives a first international guide has been established on a core theme in support and care for people with an intellectual disability. For the first time a collaboration of authors from diverse countries publish their thoughts, research and guidelines on emotional development.

Methods Presenting an international accessible guide on emotional development in relation to intellectual disability, by editors and authors.

Design: Short introduction of the guide and reason of publication - Discussion on the main themes, perspectives and relevant research - Discussion on 'what's next' and dissemination of the theme and manual

Results/Aims Create an official moment to present the guide for an international audience and create participation to establish more sharing and research on emotional development for people with intellectual disability. Let this guide be a first one.

Conclusions The guide provides the most recent international knowledge on a core theme.

From Science to Practise In using this guide support staff is provided with the latest knowledge for support and care. It shares theoretical viewpoints and practical methods and interventions for diagnostics and every day care for people with IDD.

Topic: Legal and Forensic Issues, Restraints (RT-3 E/OS)

Practical implications for discharge of restricted patients in England

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Keywords Legal, forensic issues, Quality of Life , Wellbeing

Background NHS in England has an ambitious transformation programme for people with an intellectual disability and/or autism. Improving peoples lives by ensuring that they can live in the least restrictive environments possible with a particular focus on reducing the need for long term detention in hospital and meeting their needs in the community is central. A number of important court judgements (MM and PJ) have impacted on the ability or otherwise to discharge some patients from hospital into the community. Evidence within the NHS in England has indicated that these judgements have impacted on practice meaning that commissioners and clinicians do not fully explore all opportunities to navigate a discharge pathway for people with complex restrictions.

Methods The practice approach focused on three distinct areas:

1. Analysis and understanding of the long-stay cohort of patients and thematic analysis of needs.
2. Upskilling local professionals based upon training needs analysis.
3. Individual case building plans which reduce risks and navigate complex discharge processes.

Results/Aims Training and development evaluated highly-significant improvement in knowledge base & confidence in practice. Numbers of individuals on all types of restrictions have reduced but especially section 37/41. The reductions are directly attributed to the interventions delivered.

Conclusions Knowledge transfer radically changes the pathways for people on a complex restriction, This is based upon the law in England, but transferable experience (although not the detail of law) will be applicable to other countries.

Topic: Empowerment and Independence (RT-7 G/OS)

"This is how I want to live!" Results of a study to identify housing wishes with people with complex disabilities

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1. Evangelische Hochschule Rheinland-Westfalen-Lippe, 2. Stiftung Bethel, Bethel.regional

Keywords Complex disabilities, choice, housing options, personal future planning, augmentative and alternative communication (AAC)

Background According to Article 19 of the UN Convention on the Rights of Persons with Disabilities, people with complex disabilities must have the same choices as other people. This is also reflected in the German “Bundesteilhabegesetz (BTHG)”, which stipulates that the living area "housing for people with disabilities" is regulated in the same way as for other people. However, people with complex disabilities have so far lived predominantly in larger communal living arrangements. The extent to which this corresponds to their choice remains, as they are often unable to verbally articulate their own wishes.

Methods The aim of the project "Wahlmöglichkeiten sichern" (2016-2019), funded by the Stiftung Wohlfahrtspflege was to develop and evaluate methods that enable the identification of housing wishes with those people.

In addition to systematic literature and interview studies, 11 residential wish-discovery processes and their scientific support formed the core of the project work. Methods from

"Personal Future Planning", "Augmentative and Alternative Communication" and some other approaches and methods were individually adapted to the respective person.

Results/Aims In the participatory process, methods of determining (living) wishes for people with complex disabilities were (further-)developed. Important findings with regard to the expression of will and desire as well as inhibiting and promoting factors in the ascertainment and implementation of housing wishes were identified.

Conclusions Identifying and realising housing wishes with people with complex disabilities is not a one-time event; rather, it takes place in small steps. Important are individually adapted methods, sufficient time and the recognition of his or her (wish-)expressions.

From Science to Practise The project results including recommendations for practice will be presented and discussed.

[Topic: Inclusion, Society and Community \(RT-6 G/OS\)](#)

Covid-19 pandemic and its consequences for people with intellectual and developmental disabilities

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Keywords Covid-19, Inclusion, Psychotherapy, Psychiatry, Pedagogy;

Background Covid-19 pandemic has dominated public life in Germany and around the world. The dissemination of infections has increased the number of Covid-19 cases, the related mortality and long-term effects to

dangerous levels. In order to curb the pandemic, many far-reaching restrictions of public activities and reduction of social contacts have been ordered for health, rehabilitation, and social services for people with disabilities.

Methods Selected data from a broad survey of the German Association for Rehabilitation (more than 6000 participants) will be presented. Video interviews recorded with people with disabilities, their relatives and caretakers will be shown. The reports of participating experts are based on their own professional experiences.

Results/Aims The round table will discuss the manifold consequences for people with intellectual and developmental disorders from psychotherapeutic, psychiatric and pedagogical perspectives.

Conclusions The Covid-19 pandemic has had serious negative impacts on social inclusion. People with disabilities, chronic diseases and others in need of care have been severely affected. However, some groups may have benefited from fewer demands and more stable settings.

From Science to Practise It is hoped the discussion will help to develop ways to mitigate negative effects in practice.

Posters English and German Online

Topic: Quality of Life and Wellbeing

A qualitative analysis of first lockdown living circumstances of people with intellectual developmental disorder in Germany

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Background The COVID-19 pandemic has brought significant changes to the daily routines of people with intellectual developmental disorder (IDD), affecting both their health and well-being. In Germany, this included during the first lockdown (mid-March till mid-May 2020) contact restriction and visiting bans in residential facilities, the closure of workplaces including care areas, changes in daily routines, and a higher likelihood of quarantine. This study reflects on the specific health and well-being consequences of the pandemic for people with IDD, in light of their respective socio-emotional development (SEO-concept; Došen, 2010; Sappok & Zepperitz, 2019).

Methods Within a constructed sample (n=20) based on reach and representation (vgl. Geyer, 2003), online-semi-structured interviews were conducted (April to July, 2020). Responses were transcribed and analysed by structural content analysis (Mayring & Fenzl, 2014). The sample consists of people with IDD and sufficient communicative abilities, relatives, caregivers,

managers of residential facilities, and social-pedagogical and psychological professionals.

Results/Aims The results suggest that mentally most people with IDD – who did not suffer from an infection – came through the first lock-down period in Germany relatively well. Differences in mental stability were related to levels of stability and care within the social structure. Major themes identified were the provided or lack of stability, supporting or overburdened social environment, appropriate or overloading individual demands, and sufficient or missing social contact.

Conclusion/From Science to Practise The stability and mental health of people with IDD would thus benefit from several changes learned during the pandemic-lockdown, that would take better into account the heterogeneity and individuality of people with IDD.

Keywords COVID-19, intellectual disability, public health, qualitative study, heterogeneity, daily routines, social contacts

Soothe:First Response to Mental Health Problems in People with intellectual disability

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Background: People with intellectual disabilities experience poorer mental health than the general population due to different actors. The main goal is to build strategies to minimize the psychosocial needs of people with HD and intellectual disability problems in middle and old age.

Methods: The project is based on a qualitative and applied research method with a phenomenological position. Using different techniques: eQuilt (electronic collage), Focus Group, to know the concepts and factors that people with intellectual disability identify as relevant in the promotion or worsening of MS with the idea of finding ways to improve and maintain mental health by helping of technology

Results/Aims:Factors such as depression, anxiety, stress or social discrimination, loneliness and disruption to your daily life and routine are described as relevant and negative for mental health. Music, relaxation and interpersonal contact are positive factors. Creation of visual spaces to be able to carry out activities that encourage the achievement of positive factors.

Conclusions: Co-creation and technology as allies to maintain mental health

From Science to Practise The inclusion of people in the process of creating new ways to meet their psychosocial needs helps them to bond and have greater satisfaction.

Keywords Intellectual Disability, Mental Health, empowerment

The Impact of Mental Health of Proxy Respondents on Health-Related Quality of Life Data in Intellectual Disabilities

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Background In adults with intellectual disabilities, health-related quality of life (HRQoL) is often measured by proxy-report, despite studies examining agreement between self- and proxy-report HRQoL showing poor agreement. This study investigates whether mental health of proxy-raters in intellectual disability impacts the way they rate HRQoL by influencing convergence of HRQoL ratings between themselves and the care-recipient.

Methods One hundred and ten caregivers of adults with intellectual disability completed measures of psychological distress (Kessler-6) and HRQoL (EQ-5D-3L) for themselves and the care-recipient. Convergence scores for HRQoL were calculated for subjective and objective HRQoL outcomes. Multiple regression models were fitted to estimate the association between proxy psychological distress and convergence scores of subjective/objective HRQoL.

Results/Aims The aim was to test whether mental health problems in caregivers of adults with intellectual disability are associated with greater convergence between self-reported HRQoL ratings and proxy-reported HRQoL ratings. There was a significant relationship between psychological distress and subjective HRQoL convergence scores (-0.236; $p=0.030$). There was no relationship between psychological distress and objective HRQoL convergence scores (-0.158; $p=0.084$).

Conclusions Carers with more psychological distress report more similar subjective HRQoL scores between themselves and the care-recipient.

From Science to Practise This study highlights the importance of inclusion of people with intellectual disability in their own care rather than a reliance on proxy reports. It has encouraged the use of self-completion measures when assessing HRQoL and if this is not possible proxy measures should use objective scales. When using subjective measures, the clinician is more mindful of the mental health of the proxy respondent and how this may influence data.

Keywords: Health Related Quality of Life, Intellectual Disabilities, Proxy-Reports, Mental Health

Burnout detection of professional and family carers of people with Intellectual Disabilities during confinement due to COVID.

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- 1 Institución: Althaia Xarxa Assistencial Universitària de Manresa, Fundació Privada.

Background In March 2020, general population confinement was required due to the pandemic caused by the COVID-19 virus, affecting a high number of people with Intellectual Disabilities . Some of the people with identification live in private homes with their families, but others are linked in residential resources or housing, with the support of professional educators. We must keep in mind that many people with intellectual disability have adaptive difficulties and support needs based on their ability to autonomy and that they require attention to a greater or lesser degree of professional caregivers to ensure proper day-to-day functioning. The prolongation of the situation described has resulted in significant wear and tear in both family and professional caregivers.

Methods It is a cross-sectional observational study. The first phase consists of anonymous data collection of the profiles described by means of an initial survey and later an anxiety and depression questionnaire for the two groups and a validated burnout questionnaire for professionals of people with intellectual disability, and a validated questionnaire for the burden of the main caregiver of dependent people, the latter for family members. In the second phase, it is intended to carry out a descriptive statistical analysis of the results.

Results/Goals This descriptive study aims to detect the presence of exhaustion in family and professional caregivers of persons with identification during the confinement period.

Keywords Intellectual disability, Burnout, Family carer, Professional carer, COVID19.

Possibilities of animal-assisted pedagogy for people with intellectual disabilities - A Luxembourg case study

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Aims By participating in the offers of animal-assisted pedagogy, the quality of life of people with intellectual impairment should improve, especially with regard to their personal satisfaction, their working skills, their relationship,

contact and communication skills as well as with regard to the reduction of emotional crises, fears and escalations.

Method The PERMA model of positive psychology (Positive Emotions, Engagement, Relationships, Meaning, Accomplishment) according to Seligmann (2011), in which he summarizes the empirically proven factors of human subjective well-being, form the basis of the animal-assisted interventions at the Institut St. Joseph in Betzdorf, Luxembourg. Animals provide a special motivational stimulus that addresses people holistically: socially, emotionally, physically and intellectually.

Based on an analysis of the current situation in connection with an individual formulation of goals, feedback was obtained from the persons participating in the animal-assisted services after a period of three months (by means of questionnaires, among other things). Once from the person him/herself, and additionally, if a clear communication was not possible, from the closest caregiver on behalf of the person, in order to be able to name the changes quantitatively and qualitatively. Film recordings will support future evaluations.

Results & Conclusion First experiences and results allow an analysis of the well-being setting and its design. Particular attention is paid to the question for whom which animal-assisted intervention is suitable and which individual effects can be observed?

From Science to Practise The well-being that people can experience in the animal-assisted setting creates an open energetic state of consciousness, a way of life that goes hand in hand with positive energy. This makes learning and development possible.

Keywords animal-assisted pedagogy, intellectual disabilities, PERMA-Model

[Topic: Ageing/Lifespan](#)

A strategic approach to elderly individuals with intellectual disability affected by death

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Background “Montserrat Residence” is a residential service for 40 adult men with intellectual disability. They were admitted during either childhood or adolescence and now have a mean age of 75 years old. Many of the residents are living with symptoms related to their disability, as well as symptoms associated with age-related declines and comorbidities. They have also been faced with deaths of family members and residents.

Methods Adopting a person-centered care approach in a residential service for older people with intellectual disability to improve healthcare safety, well-being and quality of life, with a special focus on the impact of death of relatives and friends, end-of-life planning and death anxiety.

- **Results/Aims** To conduct interviews with the residents to understand their experience, wishes, fears around death and to support them through bereavement of loved ones (family members and other residents). To interview family members to ascertain details of residents family history and understand the impact the of death the person with intellectual disability might have on them.
- To aid caregiving staff in the residence in their approach to death.

Conclusions Engaging with the residents in a meaningful way has helped to create a better relationship with family members. The interviews have helped to review family history, personal data and aided in the creation of a plan led by residents, which is supported by family members, carers and practitioners, including advanced care planning and end-of-life care decisions.

From Science to Practise As the average life expectancy increases, so do those with intellectual disability. The approach to death of the relatives of those with intellectual disability, as well as their own, should be a priority of residential services for elderly individuals with intellectual disability.

Keywords Ageing/Lifespan, Quality of Life and Wellbeing Families Empowerment and Independence

Topic: Mental Disorders

A survey on mental health services for adolescents and adults with intellectual disabilities

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.Background A newly established national advisory unit on mental health in intellectual disabilities in Norway investigated the organization, availability, possible adaptations, and barriers for access to mental health services for patients with intellectual disability. In Norway, both mental health and habilitation services admit patients with ID and mental health problems.

Methods A survey on services as mentioned above was distributed in all Norwegian hospitals giving specialist services. A total of 81 units replied, covering all 21 hospitals.

Results/Aims The aim was to identify facilitators and barriers related to access to mental health services for patients with intellectual disability.

Specialized units for patients with intellectual disability appeared to provide high quality services. Regarding barriers, the survey revealed 1) limited competence, 2) lack of resources necessary to adapt knowledge-based methods and to establish therapeutic relations with the patients, 3) that poor organization and collaboration between mental-health and habilitation units hampered clear priority for the patients, 4) limited access to the specialized units.

Conclusions Patients with intellectual disability do not have equal access to mental health services. Downgrading of patients with intellectual disability needs to be addressed and action must be taken to guide the hospitals to provide the same mental health care as for others.

From Science to Practise The results provide documentation for stakeholders working for better mental health services for patients with intellectual disability

Keywords Specialized mental health services, access, organizing, competence, intellectual disability

National Advisory Unit on Mental Health in Intellectual Disabilities, Norway
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Background Mental health in patients with intellectual disability is regarded by the Norwegian health authorities as a field in need of more knowledge and research. Equal access to mental health care for patients with intellectual disability is hampered by limited competence among professional health workers in general mental health, addiction services, and in habilitation services.

Methods Over the last decade, a regional specialized mental health unit for intellectual disability at the Oslo University Hospital has targeted a national advisory unit for the patient group. Several professionals have cooperated with The Norwegian Association for persons with intellectual disability and the Norwegian Autism Association, in order to apply for a national unit.

Results/Aims A national advisory unit for mental health in intellectual disability (NKUP) was established in 2019 at the Oslo University Hospital. The main obligation of the NKUP is to contribute to improved clinical services for the patients. The NKUP has 2.7 positions, divided by five employees. In 2021, the

NKUP has established two national networks and a website. Furthermore, provides weekly webinars, web seminars, on site lectures for students and clinicians. The NKUP initiates and participates in research and development projects.

Conclusions The NKUP activities are based on 1) clinicians' needs for upgrading their competence, 2) research, and 3) input from patient associations. In order to achieve the NKUP's long term aims, the unit must appear relevant to actual clinicians in both mental health and habilitation services.

From Science to Practise Increased nationwide competence among clinicians may improve mental health services for patients with intellectual disability.

Keywords knowledge, research, competence, intellectual disability.

[Topic: Physical Health / Health Inequalities](#)

Covid-19 and people with Intellectual Disability; a study from a region in Spain
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Background There is little information about COVID-19 and people with intellectual and developmental disabilities (IDD). This population is vulnerable due to the high prevalence of basal comorbidities and their characteristics and social limitations

Methods We did a literature review for COVID-19 in people with IDD and we have created a survey to analyse the situation in our region.

Results/Aims Positive cases have been in large institutions in our health regions. The most common risk factor was age over 65 years old. There are other risk factors like in general population (obesity, hypertension, diabetes mellitus, epilepsy...). Fever and tiredness were the most common physical symptoms. Behavioural change has been detected from the beginning of the pandemic to the present. The evolution in our sample is variable; from recovery to medical complications. More than a half had to be hospitalized and in 25, (71%) we had to adjust their psychopharmacological treatment due to interactions with the specific drugs of COVID-19

Conclusions: The current pandemic poses specific challenges to people with IDD. The COVID-19 response must be disability inclusive. The management should be specific and customized to people with IDD.

From Science to Practise This work provides knowledge of health situation in our region and allows to carry out preventive and early actions for people with IDD

Keywords COVID-19, coronavirus, intellectual and developmental disability, IDD

Topic: Developmental Neuroscience

Epilepsy and Intellectual Disability

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1,2,3,4 SESM-DI: Althaia Xarxa Assistencial Universitària de Manresa, Fundació Privada.

Background Epilepsy is a chronic neurological disease with a prevalence of 0.5-1%. Its etiology affects both sexes equally. Intellectual Disability is a neurodevelopmental disorder that affects between 0.7% -1.5%. Both disorders produce alterations at the bio-psychosocial level that can significantly interfere with the different functional areas.

According to the DSM-5 criteria, to carry out an evaluation it is necessary to take into account the cognitive and adaptive capacities affected during neurodevelopment.

Methods The study was carried out through a bibliographic search review through the main databases and selecting the articles according to the inclusion and exclusion criteria. Finally, 25 articles were eligible for inclusion in the systematic review.

Results/Objectives How the anatomical, physiological and psychological alterations produced by epilepsy can generate disability as well as its impact on the daily life of the person

Conclusions Epilepsy is an etiological factor of Intellectual Disability. Severity is associated with the type of epileptic seizures, being generalized seizures those that produce the greatest disability. The evaluation of the person, the only exploration of intelligence quotient (IQ) is not very representative. It is essential to take into account the specific cognitive abilities, adaptive skills comorbid disorders, social factors to determine strengths and weaknesses and establish a profile that allows different systems to provide support for each person in all areas.

From science to practice It is necessary to have updated studies on epilepsy as a source of disability to be able to make an accurate profile and define the needs of each person.

Keywords Intellectual Disability, Epilepsy, Cognitive Deficits, Neuropsychology, Neurodevelopment

Topic: Models of Care and Support

Guideline adherence of psychotropic medication in residential homes

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Background It is well-known and causes concern that psychotropic medication (PM) for adults with intellectual disabilities is often not prescribed and applied according to existing guidelines. In order to effectively lead to the desired improvement, conditions for implementation of guidelines in daily practice as well as barriers to guideline-based treatment need to be identified and subsequently systematically addressed. The aim of this study was to identify general conditions of care that are associated to guideline adherence and thus potentially affect guideline adherence.

Methods Against this background, we asked staff of residential homes to assess the extent to which PM prescription of residents with intellectual disability is carried out in accordance with current guidelines. Via n=1,530 e-mail addresses, staff from all over Germany received an invitation to process a self-developed data entry form. Altogether, n=350 staff members completed the form.

Results/Aims Ratings differed depending on staff characteristics and were associated with numerous facility-specific factors. Especially modalities of collaboration with different groups of medical specialists and the modes of regular medical visits were related to the overall assessments of the PM guideline adherence.

Conclusions PM prescription practice of adults with intellectual disability living in residential homes is likely to be improved by establishing enhanced cooperation between the staff and the prescribing physician.

From Science to Practise The cooperation between staff of residential homes for adults with intellectual disability and PM prescribing physicians needs to be enhanced.

Keywords intellectual disabilities, psychotropic medication, guideline adherence

[Topic: Ethics and Human Rights](#)

Ideas against poverty! Citizens with Intellectual Disability act to reduce social exclusion and poverty: Erasmus +

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Background This project has been framed in the European Disability Strategy 2010-2020 and in the European Platform against Poverty and Social Exclusion. His aim was to encourage people with intellectual disability to actively

participate in the search for solutions to reduce this situation in European territory.

Methods Professionals and students with Intellectual Disabilities from the four European country partners *, worked together to understand the concepts of poverty and social exclusion.

They have found and created ideas to fight poverty and then they have shared their experience in transnational mobilities. They have created materials adapted to make the subject accessible to all audiences in dissemination and awareness events.

Results/Aims- The project established synergies with governmental and non-governmental entities that are dedicated to the fight against poverty and social exclusion, generating proposals and concrete actions in which our learners actively have contributed.

-Empowerment of intellectual disability people, increasing their participation, mobility and transnational exchanges.

Conclusions Two hundred students have benefited. We have carried out 34 mobilizations of people with intellectual disabilities, who have actively participated.

The institution partners have adapted their activity programs to work across the board in the fight against poverty and social exclusion. Collaborations have been initiated with entities in their environment dedicated to the fight against poverty, joint solidarity actions have been developed.

A Methodological Guide have been created, published in the four languages of the partners, in English and with pictograms.

From Science to Practise The experience of exchange, the knowledge of a different and at the same time similar reality, is an enrichment opportunity for people with intellectual disabilities.

Keywords Poverty, Social Exclusion, Empowerment, Solidarity, European Disability Strategy

[Topic: Autism Spectrum Disorder an Related Developmental Disorders](#)

Psychometric properties of the Psychopathology in Autism Checklist in a neuro-pediatric sample: A pilot study

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Background The Psychopathology in Autism Checklist (PAC) is one of very few instruments specifically developed to aid the process of identifying mental health disorders in people with autism spectrum disorder (ASD). The applicability of the instrument among children and adolescents have not been previously examined.

Methods The psychometric properties of the PAC were examined in a mixed clinical sample of children and adolescents with ASD, neurological and other neurodevelopmental disorders ($N = 91$).

Results/Aims The participants were 2 to 17 years of age ($M = 8.38$, $SD = 4.06$; 62 boys and 29 girls). Internal consistency was adequate to good for all the subscales with the exception of the PAC Anxiety (α range = .69–.82). Test-retest reliability was adequate for all PAC subscales with the exception of Psychosis ($r \geq .60$). The PAC showed meaningful overlap and differentiation with the Strengths and Difficulties Questionnaire, the Aberrant Behavior Checklist, The Vineland Adaptive Behavior Scale, and IQ in the ASD sample ($n = 24$). The ASD sample had significantly elevated PAC Adjustment and OCD scores compared to a control group of children with specific developmental disorders ($n = 28$).

Conclusions Preliminary findings indicate promising psychometric properties for the PAC, with the exception of the Anxiety subscale, among children and adolescents with ASD.

From Science to Practise As effective treatment is available, identifying concurrent mental health conditions in children and young people with ASD is very important. In this regard, preliminary findings from the current pilot study indicated that the PAC has the potential to contribute useful clinical data, but with limitations.

Keywords autism spectrum disorder, mental health, psychometrics, psychopathology

Topic: Genetic Syndromes

Psychopharmacological prescription rates for people with Smith-Magenis syndrome

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Background Smith-Magenis syndrome (SMS) is a genetic neurodevelopmental disorder caused by a 17p11.2-deletion or *RAI1*-mutation and is associated with intellectual disability, severe sleep disturbances and challenging behaviors such as temper tantrums and self-injurious behavior. In addition to behavioral

approaches, psychopharmacological treatment is often necessary for managing these problems. In the absence of evidence-based guidelines, prescriptions are often clinician experience-based. In the Netherlands, a multidisciplinary outpatient clinic has gained years of experience in treating patients with SMS.

Methods A retrospective chart review was performed recording data on genetic mutation, age at last assessment, sex, level of intellectual disability, psychiatric comorbidity, and psychopharmacological prescriptions.

Results/Aims We aimed to study prescription rates of psychopharmacological medications in patients with SMS. We included data of 85 patients with SMS (47% female), of whom 65 had a 17p11.2- deletion (76.5%) and 20 a *RAI1*-mutation (23.5%). Median age was 13.0 years (range 0.3-45.3 years). At least 47 patients had an ID (55%) (n=19, unknown). Sixteen (19%) had a psychiatric diagnosis. In total, 58% of patients had a record of psychopharmacological treatment. Antipsychotics (40%) and stimulants (25%) were most often prescribed. Five patients had a record of coprescription of antipsychotics and stimulants. Psychiatric comorbidity was significantly associated with psychopharmacological treatment. Prescription rates were not associated with genetic mutation, sex, or level of intellectual disability. Most reported side-effects were extrapyramidal symptoms (n=6) and weight gain (n=5), attributed to risperidone.

Conclusions Psychopharmacological medications are prescribed to more than half of patients with SMS.

From Science to Practice This retrospective file review is part of a larger study enabling future evidence- and practice-based guidelines for SMS.

Keywords Genetic Syndromes, Challenging Behaviour, Mental Disorders, Pharmacotherapy

Topic: Emotional Development

Translation an adaptation into Spanish of the Scale of Emotional Development-Short (SED-S)

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Background Based on an understanding of the development of emotional functioning, Anton Dosen (1990) designed the Scheme for the Assessment of Emotional Development (SAED) to assess levels of emotional development according to a five-stage model based on the normative trajectory of typical development.

The objective of the authors when creating the Scale of Emotional Development-Short (SED- S) was to have a short psychometrically sound scale for the evaluation of the levels of emotional development in adults with intellectual disabilities, which complements existing tools and was suitable for diagnostic and scientific purposes. It is essential to have this tool in Spanish.

Methods The German version of the SED-S was translated into Spanish, following the process of retro- translation and cultural adaptation. The Spanish version was reviewed by a group of clinical psychologists and psychiatrists expert in the field of intellectual disability and research. It was administered by three expert professionals, in order to evaluate its applicability, utility and functionality, to a sample of N=10 adult inpatients with ID and co- occurring [mental or behavioral disorders](#).

Aims/results The aim of this project is to translate and adapt the SED-S into the Spanish language. Based on the assessment and consensus of the experts, some adjustments have been made for later editing.

Conclusions The Spanish adaptation of the SED-S could contribute to improving the assessment of individuals with ID, facilitating its accessibility and use to the Spanish-speaking community.

From Science to Practice This research adapts the SED-S into a different European language, enabling the use of new assessment tools and therapeutic approaches to people with ID from different cultural backgrounds.

Keywords Emotional Development, Behavioral disorders, Autism Spectrum and Related, Developmental Disorders, Mental Disorders, Assessment.

Translation and adaptation of the Scale of Emotional Development - Short into the Catalan language

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1,2,3,4,5Parc Sanitari Sant Joan de Déu

Background The prevalence of psychiatric disorders and challenging behavior in individuals with intellectual disabilities is several times higher than in the general population. The level of emotional development (ED) has been found to be a key factor in determining the adaptative behavior and mental health problems shown by individuals with ID. The Scale of Emotional Development – Short (SED-S) is a short and practical tool to assess ED in individuals with intellectual disability.

Methods The German version of the SED-S was translated into Catalan, following the process of retro-translation and cultural adaptation. The Catalan version was reviewed by two expert professionals in the field of psychology, intellectual disability and research. It was administered by three expert

professionals, in order to evaluate its applicability, utility and functionality, to a sample of N=10 adult inpatients with intellectual disability and co-occurring mental or behavioral disorders.

Results/Aims The aim of this project is to translate and adapt the SED-S into the Catalan language. Based on the assessment and consensus of the experts, some adjustments have been made for later editing

Conclusions The Catalan adaptation of the SED-S could contribute to improving the assessment of individuals with intellectual disability, facilitating its accessibility and use to the Catalan-speaking community.

From Science to Practise This research adapts the SED-S into a different European language, enabling the use of new assessment tools and therapeutic approaches to people with intellectual disability from different cultural backgrounds.

Keywords Emotional Development, Behavioral disorders, Autism Spectrum and Related, Developmental Disorders, Mental Disorders, Assessment.

Topic: Families/Parenting

Well-being and family burden of caregivers of people with intellectual disability and mental health disorders.

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Keywords Intellectual disability, mental health disorders, well-being, caregivers, family burden.

Background There are few studies on psychological well-being (PW) and family burden (FB), essential aspects to improve quality of life and mental health disorders of people with intellectual disability (ID) and mental health disorders (MHD) as well as of their caregivers.

Methods Sample: pairs of 242 participants (user-caregiver), divided into two groups of which 38.8% are adults (<18 years) with ID from FCV Madrid and 61.2% with ID-MHD linked to three community care services, PSSJD Barcelona. Inclusion criteria: caregivers and users living at family home with mild/moderate degree of ID and mental health disorders, clinical diagnosis according to ICD-10. Instruments: users: WAIS-III, PAS-ADD Checklist. Caregivers: ECFOS-II Family Burden Interview, Ryff-Psychological well-being scale and sociodemographic questionnaire.

Aims/Results Analyse the psychological well-being and its dimensions and the family burden (global and by variables) within two groups of samples of caregivers. In the ID group significant correlations were found in the PW: *positive relationships, self- acceptance and environment control* and the global

FB ($p=0.000-0.0005$). The ID-MHD group shows that *self-acceptance*, *environment control and life purposes* ($p=0.003-0.034$) correlate significantly with global FB. In both groups, *self-acceptance* and *environmental control* correlated significantly with all FB/ECFOS-II variables.

Conclusions The psychological well-being and family burden of caregivers of people with ID and ID-MHD shows that less self-acceptance and environmental control is related to higher family burden in several of its relevant variables.

From science to practice Further knowledge about the emotional status of our users' caregivers allows us to carry out early detection and to focus on users' networks and family group care, which increase their psychological well-being.

Topic: Sexuality/Partnership

Sexual assistance and sexual accompaniment in assistance for people with disabilities

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Background The United Nations Convention on the Rights of Persons with Disabilities gives rise to the right of people with intellectual disabilities to sexual self-determination. This results in the goal of empowering people to make decisions as independently as possible and to be able to make their own experiences. Sexuality is a space of experience that people with a disability would like to experience. A modern sexual assistance with trained specialists can remove obstacles in the experience of sexuality.

Methods At a symposium, lectures and workshops dealt with sex education work in institutions for people with intellectual disabilities, with the concept of sexual accompaniment and with legal issue. We were particularly interested in the areas of sex education, psychology, law, therapy and body work.

Results/Aims The aim was to make an important topic more heard and to look at some pieces that could lead to a solution. Despite the difficult legal situation, work was not only carried out on naming problems and obstacles, but constructive ideas were generated and evaluated.

Conclusions Central obstacles that were identified were the lack of offers, social prejudices, the misunderstanding of the needs as well as the legal gray area of maturity and self-determination. Possible solutions to this were new ways of satisfying needs, better information offers for institutions, the desire for recognition of the profession of "sexual assistant" and new legislation.

From Science to Practise We opened up the topic of sexual support and accompaniment in our facility. It is discussed in many areas. The residents or

carers as the voice of residents can express needs and solutions are sought. We are in contact with the agencies and ministries to achieve a change in law.

Keywords Sexuality, self-determination, sexual assistance

Topic: Empowerment and Independence

The use of assistive technology by a patient with intellectual disabilities in the home office - a case report

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Background People with intellectual disabilities can suffer various forms of difficulties in reading, memory, attention, action planning and action execution, which can affect their daily activities.

Methods A 20-year-old female with intellectual disabilities received two tasks every day over two weeks while working in home office. During the first week she was supported in performing the tasks using a paper-pencil checklist. During the second week she used the action planning RehaGoal App as assistance. The Cultural Probes method was used to assess the participant's challenges and needs in completing the tasks. Therefore, she received a set of tools for task completion as well as necessary materials, daily schedules, voluntary tasks and a questionnaire. Before and after each task, the participant was asked to report her current feelings using self-assessment stickers and to answer a question about her current motivation. After completing each task, she was asked to reward herself with self-reward stickers.

Results The participant reported being prouder, less tired, happier and more relaxed during the second week. She completed more voluntary tasks. In the second week, her task execution improved by up to 17%. In particular, the improvement was seen in two of the most challenging tasks.

Conclusion The use of the RehaGoal App led to more positive emotions and increased motivation. Accordingly, it can contribute to a better success of inclusion in the job market for people with intellectual disabilities. Critically, some tasks in the study may not have been difficult enough, resulting in a ceiling effect.

From Science to Practise Assistive technologies like RehaGoal App can lead to more positive emotions and increased motivation.

Keywords intellectual disabilities, assistive technology, planning, cultural probes, app

Posters Onsite

Topic: Mental Disorders

Use of antipsychotics in people with intellectual disability without psychosis

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Keywords: Antipsychotic, Affective disorder, Challenging behavior, Intellectual disability

Background Antipsychotic drug use are more frequent than the prevalence of psychotic disorders in adults with intellectual disabilities (ID). Few studies have looked at other factors than challenging behavior in adults with ID that uses antipsychotic drugs. More knowledge about characteristics of people with ID that uses antipsychotics drugs without a psychosis disorder are needed.

Method Of the total sample (N=593), 83 people without previously diagnosed psychosis and without current psychosis disorder used antipsychotics (Table 1). These constituted group 1, while the rest of the group constituted group 2. Bivariate logistic regressions, with group affiliation as outcome measure, was performed in three steps: univariate analysis of each dependent variable, multiple regression analysis of significantly associated variables (full model) and a final model with significantly associated variables in step 2.

Results Age, severe ID, autism, previous anxiety, previous affective disorder, and current challenging behavior were significantly associated with group 1 affiliation. The effect of ID, autism and previous anxiety disappeared when all variables were included in the analysis. The final model showed a significant association between group affiliation and age (OR=1.03, p=.003), previous affective disorder (OR=3.59, p=.001) and challenging behavior (OR=2.13, p=.007).

Discussion Previous affective disorders and challenging behaviors were associated with antipsychotic drug use in adults with ID. This indicates that the group has severe and complex difficulties with emotionally dysregulated problem behavior (EDPA). The frequent use of antipsychotic drugs in the presence of challenging behavior is problematic.

From research to practice In the presence of EDPA, antipsychotics drugs may be needed in an initial stabilizing phase of treatment. However, the pharmacological treatment should be evaluated following stabilization, and further treatment should be decided by a comprehensive psychological evaluation.

Undiagnosed psychosis in intellectually disabled autistic adults with OCD symptoms

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Keywords Psychosis, OCD, autism, differential diagnostics

Background Overlap between psychosis and obsessive compulsive symptomology has been described in the general population. Despite autistic individuals displaying apparently increased prevalence of psychotic disorders and obsessive-compulsive disorder (OCD), this possible overlap has been sparsely explored in this population. Autistic individuals frequently have difficulties verbally conveying subjective experiences, making identification of psychotic disorder particularly challenging. Behavioral manifestations of OCD may be easier for others to observe and psychotic symptoms may go undetected in individuals showing OCD- symptoms.

Methods Eighteen autistic patients with diagnosed/suspected OCD were recruited for a retrospective study using data from assessment reports. Statistical analyses were conducted for assessment tools; qualitative analyses were conducted of differential diagnostic formulations.

Results/Aims No participants were diagnosed with psychotic disorder at referral; 7/18 were diagnosed with a psychotic disorder at discharge (5 with co-occurring OCD). Psychopathology in Autism Checklist, Mini-International Neuropsychiatric Interview and Positive and Negative Syndrome Scale seemed helpful in the diagnostic assessment.

To differentiate psychosis and autism, clinicians emphasized loss of function, cognitive deterioration, disorganized behavior, and symptom duration/context independence.

To differentiate autism-related behaviours and OCD symptoms, clinicians emphasized subjective experience of symptoms as egosyntonic/egodystonic. To differentiate psychosis and OCD, clinicians emphasized developmental history, symptom trajectories, and the aspects used to differentiate psychosis/autism.

Conclusions Psychotic disorder may be overlooked in autistic individuals, possibly masked by compulsive and/or repetitive ritualistic behavior. To disentangle compound states, obtaining a thorough developmental- and symptom history was helpful.

From Science to Practise Identification of psychosis has considerable consequences for adequate treatment and care

The impact of COVID-19 on people with intellectual disabilities in Chile

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Keywords Covid - 19, Mental health, Intellectual Disability, pandemic

Background In Chile, on March 3, 2020, the first infections of Covid - 19 were confirmed. A curfew and restrictions on leaving were established. The aim of the study was to evaluate the impact of confinement on people with intellectual and developmental disabilities.

Methods A descriptive study with online survey application was used with non-probability sampling for convenience. During October 2020 and February 2021, 4 surveys were applied to: person with intellectual disability (n:178), family members (n:65), professionals (n:62) and organizations (n:26). All participants (N:331) accepted informed consent.

Results/Aims Of the total number of people with intellectual disability, 53% declared they felt fear and 66% were nervous. 93% reported missing something. They feel less control than before: 21.3% in aggressions towards others and 16.0% towards themselves. 50% in attention, concentration and memory. 22.5% in their interpersonal relationships, 25.3% in their mood, 18% in sleep and 52% feel more hungry. Family members report changes in people with intellectual disability behavior and regression in previously acquired skills. 91% of support professionals report that people with intellectual disability have been negatively affected by the quarantine situation as a result of Covid - 19.

Conclusions People with intellectual disability and their families have adapted quite well to the pandemic. Confinement has had a strong social, emotional and occupational impact on people with intellectual and developmental disabilities.

From Science to Practise Provide accessible information so that PWID can understand what is happening and what they need. Provide support to families and professionals, both emotionally, socially and financially. Help to overcome isolation, with support strategies for PWID, more information for families and more support for organizations. Protect the rights of people with disabilities.

Satisfaction and needs of psychiatric inpatients with intellectual disability

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Keywords: patient satisfaction, inpatient service, mental health, participation

Background: The involvement of patients with intellectual disability is an essential component of inpatient psychiatric treatment, as persons with disabilities have the right for the highest attainable standard of health. To attain these goals, it is necessary to query the level of satisfaction and needs in persons with intellectual disability. Moreover, it allows persons with intellectual disability who are often overruled to experience self-efficacy.

Methods: The needs and satisfaction of 272 patients with intellectual disability who used our psychiatric inpatient service were assessed systematically with the German adaption of the Client Satisfaction Questionnaire-8 (ZUF-8) between 2015 and 2019. In addition, we collected qualitative data to assess specific opinions regarding the eight prompted items in the questionnaire.

Results: Most people (92%) were satisfied with the quality of the treatment and would recommend the BHZ to others (85%). The treatment met all or most of the requests for 85% of the inpatients and even more (89%) were overall content with their treatment. In the qualitative evaluation, in particular the food (84%) and the building design (97%) were criticized, while the staff and the therapy offers were mostly rated positively (87% each).

Conclusions: The standardized assessment of the satisfaction with the treatment in a hospital provides useful information to further improve the services. It is important to evaluate the medical services on a regular basis in order to offer appropriate treatment and care.

From Science to Practice: Appropriate treatment and care is indispensable in inpatient treatment of persons with ID, as patient satisfaction contributes to recovery.

Impact on mental health and behavior in people with intellectual disabilities of the COVID-19 pandemic

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Keywords: mental health, challenging behaviour, COVID-19

Background The impact of the COVID-2019 pandemic concerning our mental health seems evident. Several studies report an increase of anxiety and depression in general population but little is known about the mental health and behavioural consequences in people with intellectual disabilities. This is the first study reporting the psychological impact of the Covid-19 pandemic in people with intellectual disabilities in Catalonia.

Methods A group of adults with intellectual disabilities were evaluated at three different times during one year (before pandemic, lockdown, post-lockdown) surveying demographics, psychopathology and behaviours, cognition and caregiver overload. They were assessed with MiniPass-ADD and DASH-II for mental health, Aberrant Behavior Scale for behaviour, HoNOS-LD and Zarit Scale for caregiver burden.

We use descriptive statistical analysis, tests χ^2 and analysis of variance to make comparisons between groups of dichotomous and continuous variables. Cluster analysis was performed to determine subgroups of greater vulnerability.

Results 249 PwIDD were included: 54% men, ID level (F70 36%, F71 34%, F72 30%), and ASD (41.3%). The impact of the different pandemic phases on mental health and behaviour is low. A reduction in behavioural problems during the lockdown phase has been observed in those who live in their homes and in residential centers. During the semi-confinement phase, behavioral improvement is maintained in those who reside in family and community homes. The burden of caregivers is low, being the concern for the future the most intense.

Conclusions With regard to the variables related to psychological and behavioural impact, we have found that the female, younger and ASD are the most vulnerable group.

From Science To Practice Constant support for people with intellectual disabilities and their caregivers from the specialized services are essential to guarantee a good quality-of-life and less emotional impact during traumatic episodes of emotional overload.

[Topic: Inclusion, Society and Community](#)

The usage of Social Media for communication of persons with intellectual developmental disorders

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Keywords: social media, intellectual developmental disorder

Background: Comprehensive information about and training in the usage of social media is crucial for persons with an intellectual developmental disorder (IDD) for social participation. Therefore, we aimed to assess the usage patterns of social media in persons with an IDD.

Methods: A questionnaire gathering information about the usage of the internet and most relevant topics was applied to 188 persons (99 men and 87

women, 2 persons have not specified their sex) between 18 and 75 years with mild IDD from 2019 to 2021.

Results: 123/188 persons (65,4 %) used the internet and 65 (34,6 %) did not. Those who used the internet were mostly (79,9 %) younger than 40 years, whereas the people who did not use the internet were mostly (70,7 %) older than 40 years. No gender differences could be detected. Nearly three quarters (74 %) were using the internet to relax. Internet was used when feeling bad (59,3 %) or bored (77,2 %), nearly half of the persons (43,9%) felt better while or after being "online". Almost two third (63,4 %) were using social media, especially Facebook (48%) or Instant Messaging (34,1 %).

Conclusion: Internet and social media depict an important part in life of many persons with IDD, especially the younger ones. Important topics are communication, entertainment and individual interests. Educational and practical interventions regarding the usage of Social Media are needed and asked for.

From science to practice: The influence of social media is constantly growing and takes a key role in access to social life and participation. A proper usage of social media provides a chance to improve social participation and communication of persons with IDD.

Topic: Borderline ID

The Reflective Functioning Questionnaire for people with mild to borderline intellectual disabilities: adaptation and validation

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Keywords: Mentalization, Reflective Functioning Questionnaire, intellectual disabilities, adjusting, validity

Background Mentalizing is the ability to reflect on the behaviour of the self and others in terms of mental states. The development thereof is likely to be disrupted in people with mild to borderline intellectual disabilities (MBID). However, to measure mentalizing abilities in this target group, a self-report instrument is not yet available. Therefore, the Reflective Functioning Questionnaire (RFQ) was translated and adapted. In this study, the factor structure, reliability, and validity of this RFQ was examined.

Methods Adults with MBID (N=159) completed the Dutch and easy-to-read RFQ with eight additional items. To assess the reliability and validity of the RFQ, other instruments related to mentalizing including self-report and performance-based instruments (subscale Perspective Taking (PT) of the

Interpersonal Reactivity Index (IRI), Radboud Faces Database (RaFD), and Frith-Happé Animations Test) and personal variables (autistic traits, AQ-10) were also used.

Results Confirmatory Factor Analysis confirmed the original two-factor structure of the RFQ and a two-factor structure of the extended RFQ with additional items. For both questionnaires generally satisfactory internal consistency, test-retest reliability, and construct validity were found.

Conclusions The results from this validation study supported reliability and validity of the RFQ as an instrument for assessing mentalizing abilities in adults with MBID. This RFQ may offer opportunities for gaining more clinical knowledge and conducting more research regarding mentalizing in this target group.

From Science to Practice The RFQ for people with mild to borderline intellectual disabilities can be used to assess mentalizing abilities in this target group in clinical practice, for example, to better match the actual level of the recipient in interventions aimed at improving mentalizing abilities. This study disseminates the adapted RFQ ready to use in clinical practice.

Topic: Physical Health / Health Inequalities

Reducing barriers, improving awareness: primary care liaison meeting pilot

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Keywords Reasonable Adjustments, Primary Care, Inequalities, ID Registers, Co-production.

Background Islington Learning Disabilities Partnership (ILDLP) is an integrated health and social care service for people with intellectual disability in Inner London. The service wanted to improve the interface with primary care services by offering outreach meetings. The primary goals of the meetings were to improve health outcomes for people with intellectual disability and strengthen links with primary care services and other stakeholders.

Methods Key stakeholders and the terms of reference for the meetings were agreed. Meetings were held virtually and lasted one hour. An online primary care bulletin was used to promote the pilot. Interested surgeries were asked to obtain the following information ahead of the meeting: number of patients on their intellectual disability (ID) registers, specific clinical and welfare concerns, any patients prescribed psychotropic medication without an indication and any patients requiring support for annual health checks (AHCs).

Results/Aims 9 primary care services participated over an 8 month period. Discrepancies in ID registers were evident: 28/191(15%) patients on primary care ID registers were not known to ILDP. However, 21/191 (11%) of patients were previously confirmed as not meeting ILDP service criteria. 2/191 (1%) were identified as having no indication for psychotropic prescribing. Qualitative feedback was positive, including requests for longer and more frequent meetings. Quantitative feedback revealed 5/10 (50%) responders found the meetings “useful” and the remaining 5/10 (50%) found the meetings “most useful”.

Conclusions The liaison meetings were valued by primary care services. Discrepancies in ID registers needs further evaluation.

From Science to Practise Specialist liaison with primary care may reduce health care barriers for people with intellectual disability.

Head MRI in patients with epilepsy and intellectual disabilities under general anesthesia

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Keywords Head MRI, epilepsy, intellectual disability, general anesthesia

Background In patients with epilepsy, head Magnetic resonance imaging (MRI) is recommended at initial diagnosis unless there is a typical history of genetic generalized epilepsy (Bernasconi et al. 2019). In individuals with intellectual disabilities, this examination is sometimes only possible with sedation – due to lack of cooperation or behavioral disturbances. In these cases, head MRI is performed in our clinic under general anesthesia. The risks of anesthesia need to be weighed against the chances of clinically relevant findings.

Methods Inclusion criteria: 66 patients with epilepsy and intellectual disabilities having had a head MRI under general anesthesia between January 2016 and December 2020. In case of more than one MRI in a patient, the last examination was considered.

Results/Aims The aim of this study was to characterize the included patients and to assess head MRI findings. Description of patient characteristics, indications, procedure, complications, MRI findings will be presented.

Conclusions In 85% of patients with epilepsy and intellectual disabilities, clear pathological MRI findings were detected. This rate is much higher than in

patients with epilepsy without ID (appr. 25%). The risks of the imaging procedure including general anesthesia are negligible.

From Science to Practise Patients with epilepsy and intellectual disabilities should have head MRI at low threshold as all epilepsy patients. Findings may help in estimating the cause of epilepsy, and – in some cases – the cause of intellectual disabilities. Furthermore, findings contribute to assess prognosis of epilepsy and may open the path to specific treatment options.

Behavioural changes as side effects in a patient treated with perampanel-a case report

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Keywords epilepsy, intellectual disability, perampanel, behavioral changes

Background In the epilepsy center Epilepsieklinik Tabor people with refractory epilepsy are treated. There is a focus for the treatment of people with intellectual disability and epilepsy.

Psychiatric side effects of antiepileptic drugs, in this example perampanel, are often seen and it is sometimes difficult to recognize them, especially in cases of comorbidity of intellectual disability and psychiatric disorders.

Methods We show in a case report that severe psychiatric side effects occurred under a high dose of perampanel, resulting in a longer stay in a psychiatric hospital and high-dose treatment with neuroleptics.

Results/Aims This typical example shows that perampanel sometimes can have significant psychiatric side effect. It is difficult to detect these side effects in patients with intellectual disabilities, especially with existing psychiatric comorbidity.

Therefore, it is particularly important to pay attention to possible side effects. The dosing of perampanel should be done slowly and under close observation of behavioural changes.

Perampanel is an effective anticonvulsant drug. If perampanel is clinically indicated, it should be prescribed under the control of a specialist.

Conclusions In the group of patients with epilepsy and intellectual disability, we often see psychiatric side effects in the use of perampanel, even severe behavioral abnormalities. This is impressively shown in the case report. Two studies from the Netherlands and Germany also confirm these observations.

From Science to Practise In the use of drugs with a high potential for side effects, in this example perampanel, it is particularly important to observe carefully changes in the behaviour of the person. When giving pregabalin to people with intellectual disability note: start low, go slow.

Disclosures 1Disclosure Author 1 GW pharmaceutical, UCD, Novartis, Eisai

Topic: Models of Care and Support

**Psychology students' attitudes toward people with intellectual disabilities:
Adaption & validation of the G-MAS-P**

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Keywords Attitudes, scale development, factor structure, validation

Background Attitudes of mental health professionals toward people with intellectual disabilities can have an impact on their expectations towards treating people with a dual diagnosis. To that extent, this study adapted the German version of the Multidimensional Attitudes Scale Toward Persons with Disabilities (G-MAS) into the G-MAS-P to gain insight in the perspectives of psychology students towards engaging professionally with people with intellectual disabilities and mental health problems.

Methods 98 psychology students, mostly woman (89.8 %) and with a mean age of 25 years (SD = 4.6), completed the new G-MAS-P. 80 participants (81.6%) reported to have had a prior contact with a person with intellectual disabilities. Principal component analysis with Varimax rotation was used to examine a three, four and five factor structure of the new G-MAS-P.

Results Contrary to the three-factor structure of the original MAS and the four-factor structure of the G-MAS, a five factor structure was the best fit for the G-MAS-P, explaining 57.7% of the total variance. Internal consistency of the overall scale was high (Cronbach's $\alpha = .89$) and at least satisfactory for the five identified factors: interpersonal stress (.90), positive cognitions (.77), negative cognitions (.67), behavioural avoidance (.63) and positive approach (.65).

Conclusions The G-MAS-P provides a reliable scale with a five-factor structure. Findings are discussed in light of application opportunities of the G-MAS-P and future research.

From Science to Practise By assessing the attitudes of mental health professionals toward people with intellectual disabilities within their professional context, the G-MAS-P could provide insight in their potential training or sensibilisation needs.

Topic: Emotional Development

Lessons learned from online interventions on anxiety and depression for children and adolescents

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Keywords Digital interventions, Anxiety, Depression, Mild intellectual disabilities

Background People with mild or borderline intellectual disabilities may benefit from online interventions targeting symptoms related to worrying and anxiety, but suitable interventions are scarce. The aim of this study was to extract the lessons learned from previously developed interventions aiming at typically developing children or youth, to benefit the development of new interventions for persons with intellectual disabilities.

Methods A literature review of effect-studies on online interventions targeting anxiety- and depression-relates symptoms in children and youth. Of interest were the intervention effects, adherence and user experience among other outcomes. Articles were assessed for methodological quality. Relevant data was extracted from the discussion sections relating to the factors contributing to, or hindering effectiveness and adherence of the interventions.

Results/Aims The literature review resulted in 22 articles that were analysed. Most of the interventions were based on cognitive behaviour therapy and/or psycho education and delivered online. The lessons learned that can be applied for persons with mild or borderline intellectual disabilities are depicted in a visual overview.

Conclusions Digital interventions are an accessible way to deliver treatment or prevention of mild symptoms of anxiety or depression, with adherence being a main concern. Studies in typically developing children and youth provide useful information to optimize the content and design of digital interventions for persons with mild or borderline intellectual disabilities.

From Science to Practise This information can be used when designing interventions, to support making decisions about the interventions' content, structure and implementation. Factors linked to success are a.o. keeping the sessions short, straightforward and easily accessible.

Topic: Families/Parenting

Exploring the quality of the sibling relationship: a narrative review

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Keywords sibling, relationship, Intellectual Disability, music, creativity

Background The impact of a child with Intellectual Disability on the family life has been widely researched, often from the perspective of the parents. The quality of the sibling relationship however, is important because peer

interactions in this relationship during adolescence shape the identity. This research's aim is to identify modalities that can affect the quality of the sibling relationship when one of the siblings has Intellectual Disability.

Methods A narrative review of recent studies (2000-2020) was conducted to identify different modalities that can affect the quality of the sibling relationship.

Results/Aims The quality of the sibling relationship was determined by three general modalities: (i) context involving the practical aspect of daily life, including planning, structure, home- and school-environment; (ii) role involving the different roles the siblings can assume and the consequences these roles entail; (iii) creativity involving the creative abilities and skills the siblings possess and use in interaction with their sibling with ID.

Conclusions Creativity, more specifically creativity in sibling interactions, is considerably less researched than context and role. This review points out the need for further research about creativity: which creative abilities do siblings use to interact with their sibling with Intellectual Disability? The modalities discussed here are by no means comprehensive, further research is needed.

From Science to Practise Programs to support the creative modality of the sibling relationship could be developed, like a music-based support program to facilitate the creative relationship between siblings in daily life.

Topic: Challenging Behaviour

'Think Together, Act Together'; an integrative healthcare- path for challenging behaviour

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Keywords integrative care, challenging behaviour, psychotropics, non-pharmaceutical treatments

Background In individuals with intellectual disability challenging behaviour (CB) is frequently present. Causes are physical, mental, and environmental. A multidisciplinary, integrative approach is necessary in diagnostics and treatment of CB. In clinical practice this is often hindered by barriers between healthcare sectors.

Psychotropic drugs (PD) are often used as treatment for CB's, although the effectiveness has not been proven and side-effects frequently occur. Attempts to reduce PD often fail, due to lack of non-pharmaceutical treatments and possibly also to barriers to implement integrative healthcare.

Methods A cluster-randomized controlled design is used to compare the intervention with care-as-usual (CAU). Participants are residents of intellectual disability -care providers, use antipsychotics, antidepressants and/or benzodiazepines for CB, have a developmental age <6 years and calendar age >12 years and have no dementia or chronic psychosis.

The intervention is an integrative healthcare-path provided by a specialized team of mental healthcare and intellectual disability -care professionals in which is attempted to reduce the PD-use by replacement with non-pharmaceutical interventions.

Data-collection is at baseline, 8, 16, 28, 40(end of intervention) and 52 weeks(follow-up).

Outcomes are the presence and severity of CB, PD-use and number and kind of non-pharmaceutical interventions.

Aim To investigate whether treatment of CB while reducing PD will better succeed when applying integrative healthcare compared to CAU.

Results This is an ongoing study from 2020-09-01. Until 2021-04-01 in six intellectual disability -care providers 20 participants were included.

Recruitment is hindered by organizational/cultural factors and corona-measures. Up to now, in participants complex somatic and behavioural problems, and use of restraints, including off-label PD use is common.

From Science to Practise Integrative treatment of CB will favour health by replacement of off-label psychotropic drug use by non-pharmaceutical treatments.

Topic: Genetic Syndromes

Application of P-LEVISS intervention in a person with KBG syndrome, autism disorder and severe challenging behavior

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Keywords: KBG Syndrome, ASD, challenging behaviour, P-LEVISS

Background KBG syndrome is a rare multisystemic, autosomal dominant disorder caused by mutations in ANKRD11. It is characterized by intellectual disability (ID) and skeletal anomalies. While challenge behaviour is common, the association between KBG and autism disorder (ASD) is debated. The Positive Learning Visual Structured Support based on cognition (P-LEVISS), is an intervention program which is born from the fusion of the positive behavior

support and TEACCH techniques, with a solid knowledge of the cognitive functioning of the person as a prior step to any intervention.

Aim To evaluate the efficacy of P-LEVISS intervention in a male with KBG syndrome

Methods 25years old man, affected by KBG syndrome and severe ID, ASD and challenging behavior. The subject is evaluated through different behavioral, cognitive and psychopathological scales before/after the P-LEVISS intervention

Results Tests are used at basal time and 6 months after the intervention: ABC-ECA(agitation 14 vs

4),Vineland (improvement in independence, home activities, socialization, social behavior, compliance),HONOS-LD (21 vs 18) and DASH-II(lowering of anxiety, hyperactivity)

Conclusions P-LEVISS has helped to decrease anxiety, improve behavior and independence abilities. Cognitive examination is basic to establish a P-LEVISS intervention and allows people with KBG syndrome and ASD to learn new routines, improve adaptive skills and reduce behavior.

From Science to Practise Importance of: Multidimensional evaluation; the need of establishing a neuropsychological profile before an intervention and the use of P-LEVISS program to reduce behavioral problems and to improve new abilities