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A Systematic Review of Longitudinal Trajectories of Mental Health Problems in Children with Neurodevelopmental Disabilities

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Abstract

To review the longitudinal trajectories – and the factors influencing their development – of mental health problems in children with neurodevelopmental disabilities. Systematic review methods were employed. Searches of six databases used keywords and MeSH terms related to children with neurodevelopmental disabilities, mental health problems, and longitudinal research. After the removal of duplicates, reviewers independently screened records for inclusion, extracted data (outcomes and influencing factors), and evaluated the risk of bias. Findings were tabulated and synthesized using graphs and a narrative. Searches identified 94,662 unique records, from which 49 publications were included. The median publication year was 2015. Children with attention deficit hyperactivity disorder were the most commonly included population in retrieved studies. In almost 50% of studies, trajectories of mental health problems changed by < 10% between the first and last time point. Despite multiple studies reporting longitudinal trajectories of mental health problems, greater conceptual clarity and consideration of the measures included in research is needed, along with the inclusion of a more diverse range of populations of children with neurodevelopmental disabilities.

Keywords Adolescents · Children · Disability · Longitudinal · Mental health · Trajectories

Extended author information available on the last page of the article

Introduction

Understanding when and under what circumstances mental health problems develop across childhood and adolescence can provide important information to support strategies for prevention and treatment. Gaining this knowledge requires longitudinal research into the timing and the form or shape of change (Ployhart & Vandenberg, 2010), and into the factors influencing mental health problem progression. For children with neurodevelopmental disabilities (NDD), who often display higher levels of mental health problems than their non-disabled peers (Oeseburg et al., 2010, 2011; van Steensel et al., 2011), gaining this knowledge is of even greater importance. The purpose of the present study is to provide a systematic review of longitudinal studies of mental health problems in children with NDD. In this study, we focused on child-onset neurodevelopmental or sensory disabilities, and use the word ‘child’ to refer to the paediatric period, and define it as those aged < 19 years (Sawyer et al., 2019). NDDs include, but are not restricted to, the diagnoses classified as NDDs in the Diagnostic and Statistical Manual of Mental Disorders DSM-5 (American Psychiatric Association, 2013) or as mental, behavioural or NDD in the International Classification of Diseases, ICD-11 (World Health Organization, 2020). Example diagnoses include intellectual disability (ID), autism spectrum disorder (ASD), and attention deficit hyperactivity disorders (ADHD). According to the ICD, NDDs are characterised by a “clinically significant disturbance in an individual’s cognition, emotional regulation, or behaviour...usually associated with distress or impairment in personal, family, social, educational, occupational or other important areas of functioning” (World Health Organization, 2020, p. 1). However, there are several other diagnoses listed in other parts of the diagnostic manuals that arguably also meet this definition. For example, cerebral palsy (CP) and spina bifida (SB) are primarily associated with motor disorders, but also frequently present with cognitive, emotional, and behavioural difficulties (Morris et al., 2013; Rosenbaum et al., 2007).

A mental illness diagnosis is not conceptually equivalent to an NDD, however, for some child-onset disability groups, there has been a long-standing recognition of an increased risk of mental health problems or illness, for example, anxiety disorders in ADHD (van Steensel et al., 2011) or depression in children with ASD (Gotham et al., 2015), while there has been less focus on this aspect of health for others. For example, the presence of mental illness has not commonly been explored in children with CP, although mental health problems, such as distress, loneliness and other psychosocial issues are known concerns (Dickinson et al., 2007; Power et al., 2018). One reason for keeping a broad approach to the included population in the current review, and not focusing on one diagnosis at a time, is to reduce the risk of overlooking general factors influencing mental health problems in children across diagnoses. In non-disabled children, the evidence suggests distinct trajectories for different forms of emotional and behavioural problems during various parts of the developmental period. Physical aggression, for example, seems to have a bell-shaped curve in the first years of life for many children, with increases from 12 to 36–48 months, followed by a decrease in the subsequent years (Alink et al., 2006; Girard et al., 2014; Tremblay et al., 2004). Non-suicidal self-injury, on the other

hand, typically appears in early adolescence (Cipriano et al., 2017; Nock, 2010) and decreases in late adolescence (Moran et al., 2012). For internalizing problems, such as anxiety and depression, the general tendency appears to be increasing levels in adolescence (Costello et al., 2011) which may be primarily driven by the higher prevalence in girls (Costello et al., 2003).

Studies investigating factors influencing or predicting the development of mental health problems throughout childhood in non-disabled children have focused on a broad range of factors, including child factors, such as sex or temperament, parental factors, such as parental mental health problems or parenting style, and broader environmental factors, such as socio-economic status or bullying (see for example Basu & Banerjee, 2020; Carneiro et al., 2016; Goodman et al., 2011; Moore et al., 2017; Peverill et al., 2021; Rose et al., 2018). While it is reasonable to assume these factors also play a role in the mental health trajectories of children with NDD, it is important to explore whether the presence of an NDD influences the timing of onset, or shape of change over time, or indeed whether there are additional important variables that impact mental health problem outcomes in this population. Participation in important life situations (Imms et al., 2017) is one potentially modifiable variable that may have a greater influence on the mental health of those with NDD than on children without disability, because children with NDD are known to experience significant participation restrictions (Chan et al., 2005; King et al., 2013; Shabat et al., 2021; Shattuck et al., 2011).

Careful definitions and separation of constructs are essential when discussing outcomes such as mental health problems in children with NDDs, in particular, a distinction between mental illness, mental health problems, and mental health is needed (Granlund et al., 2021). In this review, mental illness is defined as a condition meeting the threshold for diagnosis (e.g., depression, anxiety disorder, bipolar disorder, post-traumatic stress disorder). A mental health problem is defined more broadly as encompassing mental illness, but also includes problems of stress or distress that do not meet the diagnostic criteria for illness (Granlund et al., 2021). In the current review, we applied a broad definition of mental health problems, incorporating both internalizing - and externalizing problems. Including externalizing problems is important since they have been shown to predict internalizing problems later in the developmental period (Mesman et al., 2001; Wang et al., 2018). Traditionally, in diagnostic manuals, mental health has been defined as the lack of mental health problems. In the last decade, a shift towards a dual continua model in which mental health and mental health problems are seen as separate but related phenomena has been seen (Keyes et al., 2002). In the dual continua model, mental health is defined as wellbeing, using a broad definition including emotional wellbeing, psychological wellbeing as well as social wellbeing. Based on the dual continua model, this study primarily aimed to identify and synthesise the evidence from longitudinal studies of mental health problems of children with NDDs. In addition, we aimed to identify pre-disposing or ameliorating factors that influence outcomes. Further, the study sought to identify which children with NDDs appear to be most at risk of developing mental health problems. Knowledge gained will provide useful information for preventative or protective strategies, along with treatment planning and individual

support. The review question was: *For children with NDD, what are the longitudinal trajectories of mental health and/or mental health problems, and which factors moderate or mediate the development?*

Materials and Methods

Design

This was a systematic review, and the findings are reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines (Page et al., 2021). The review was prospectively registered on the PROSPERO International Prospective Register of Systematic Reviews in October 2019 (CDR42019142312).

Search Strategy

Searches were conducted in September 2019 and updated in June 2021. Six databases were searched: PubMed, Web of Science, Scopus, PsycINFO, ERIC, and PsycARTICLES. Search terms were developed for the following key concepts contained in the research question: (i) the population of interest was children aged ≤ 19 years; (ii) diagnosed with any NDD; (iii) the outcomes studied were mental health problems; and (iv) the research designs were longitudinal. A sample search strategy is included in Supplementary Table 1. The search strategy was applied with the following limits: publication type to include peer-reviewed journal articles, written in English, and published after 1990.

Study Selection

We sought studies of children and adolescents with NDDs, who were followed longitudinally, for at least two years and assessed on at least three occasions using outcome measures tracking mental health problems. The criterion of at least a two-year follow-up was used to ensure a wide enough time to identify changes in mental health problems with commonly used screening instruments. The criterion of at least three-time points was used to allow for a potential in-depth analysis of the shape of trajectories since two time points only allow for depicting change as a straight line. Inclusion and exclusion criteria were established to screen for eligible articles as described in Table 1.

The search results were downloaded with full bibliographic information, and combined into one data source. Duplicates were removed with the R package *revtools* (Westgate, 2019). Titles and abstracts were screened using the inclusion/exclusion criteria. Reviewers ($n=22$ due to the volume of records) received an Excel worksheet with a record (study/document) identification number and title/abstract for their share of documents to screen. The selection at the title and abstract screening stage was made independently by two reviewers. Any document selected by at least one reviewer at this stage of screening was included in the full text screening

Table 1 Inclusion and exclusion criteria for study selection

Criteria	Inclusion	Exclusion
Participant age	≤18 years of age (for 100% of the sample or analysable subgroup) for at least 2 of the waves of data collection	Any participant ≥ 19 years of age (or no subgroup data available to analyse within the age range)
Participant conditions	All participants, or all of an analysable subgroup, with any disability that is primarily associated with impairments in the ICF domains of seeing, hearing, mental functions, and/or neuromusculoskeletal and movement-related functions. Example diagnoses include autism, ADHD, intellectual disability, cerebral palsy, hearing or vision loss, acquired brain injury, specific learning disorders, motor disorders, and genetic conditions.	Participants described as typically developing or participants with diagnoses associated mainly with other forms of impairments (e.g., a psychiatric condition without an NDD, chronic somatic illnesses such as asthma)
Intervention(s), exposure(s)	No intervention is needed, but intervention studies can be included as long as the aim is not to affect mental health	Intervention studies where the aim is to change mental health
Comparator(s) / control	Any or none	-
Method	Studies with longitudinal design with at least 3 waves of data collection (mean time between first and last time point should be 2 years or longer) with the same measure of mental health problems.	Qualitative studies
Context	Any	-
Main outcome(s)	Any reported mental health problem outcome (e.g., anxiety, behaviour problems, depression). Can be under the threshold for diagnosis.	Any other problem, condition, or domain

stage. Full text screening was undertaken by various pairs of reviewers, blinded to each other's ratings. Disagreements about inclusion/exclusion between reviewers were resolved by a third reviewer.

Data Extraction

A standardized Excel spreadsheet was developed for data extraction. Extracted information included: study identifiers (authors, year); study setting; study purpose; participant characteristics (diagnosis, age, sex); study methodology (design, frequency, and timing of measurement, analysis approach); main and secondary mental health problem outcomes (measures, respondent/s, data); reported moderators and mediators (e.g., child's biological sex, socio-economic factors, parent factors); authors' summary of results and conclusions. Pairs of reviewers extracted data independently, and discrepancies were identified and resolved through discussion (with a third reviewer when necessary). Missing data required for the assessment of relevant studies or data synthesis was requested from the study authors. Where possible, outcome data were extracted from each included study for each mental health problem measure at each time point collected. In cases where the outcome data were visualized in graphical figures, but not presented in numbers or obtained from authors, means for each time-point were extracted using the *metaDigitise* package (Pick et al., 2018).

Evaluation of the Risk of Bias

Two reviewers (MI, CI) independently assessed each included article for risk of bias, using the Critical Appraisal Skills Programme checklist for cohort studies [CASP; Critical Appraisal Skills Programme (2018)]. Disagreements were discussed and consensus decisions were taken with the involvement of a third reviewer (HD) when necessary. Some adaptations were made to the CASP based on the specific aims and nature of the current review. First, since the question of precision of results was not possible to answer coherently across a methodologically diverse set of studies, reviewers rated all studies reporting some measure of variability positively (with a "yes"). Second, the question about whether results could be applied to the local population was answered as to whether the findings could be generalized to diverse settings since the reviewers in the current study resided in different local settings (e.g., Australia, Sweden). Third, additional criteria were added to some questions to enhance the consistency of responses by raters (see results for further description).

Data analysis

The analyses were conducted in R (R Core Team, 2022) using RStudio (RStudio Team, 2020) and the manuscript was formatted using the *papaja* package for R (Aust & Barth, 2022). Given the nature of the research question and the expected heterogeneity of included studies' methods and data, a meta-analysis was not appropriate. Therefore, a narrative synthesis, guided by Popay et al. (2006) was undertaken

to address the primary focus of the review. First, the volume (number of studies, participants, and participant groups) and quality (risk of bias) of the evidence were summarised. Findings were then summarised and described as follows: (i) the longitudinal mental health problem outcomes for those with an NDD, including populations studied, time course (i.e. length of follow-up), and identification of outcomes measured and results; (ii) studies reporting data collected using the same outcome measures were graphed longitudinally to aid in the interpretation of findings; and (iii) where there was evidence of contributing factors to mental health problem outcomes, those factors were identified and described along with strength and direction of relationships with mental health outcomes. Figures were created with the *ggplot2* [longitudinal trajectories; Wickham (2016)] and *robvis* [risk of bias assessment; McGuinness & Higgins (2019)] R packages. Mental health problem trajectories were plotted for outcomes used in more than two studies.

The narrative synthesis was used to consider patterns in outcomes along with variations across populations and settings/situations and provide guidance about at-risk groups. Groups of studies with similar populations, and/or outcomes, and/or time courses were considered together in the narrative synthesis where there were data to support this approach.

Results

Study Selection

The searches resulted in a total of 94,662 records, 80,481 in the original search in 2019 and 14,181 from the updated search in 2021. In addition, reference lists of identified systematic reviews from the searches were manually checked, which resulted in 208 more records (that were then checked for doubles and screened). From all records, only 49 publications were included. Figure 1 displays the flow of records through the review and summarises the primary reasons for exclusion. Because our review question focused on longitudinal outcomes, it was common that individual studies were reported within multiple publications over time; at least 18 of the included publications had some degree of overlap in participants with 1–3 of the other included studies.

Study Characteristics

Table 2 presents the characteristics of the 49 included publications. Most studies were conducted in the United States ($n=23$ publications), followed by the United Kingdom ($n=8$), Australia ($n=6$), Canada ($n=7$), the Netherlands ($n=5$), and one each from Switzerland, Israel, and Germany. Three studies were published in the 1990s and 13 since 2019 (26.5% of those included).

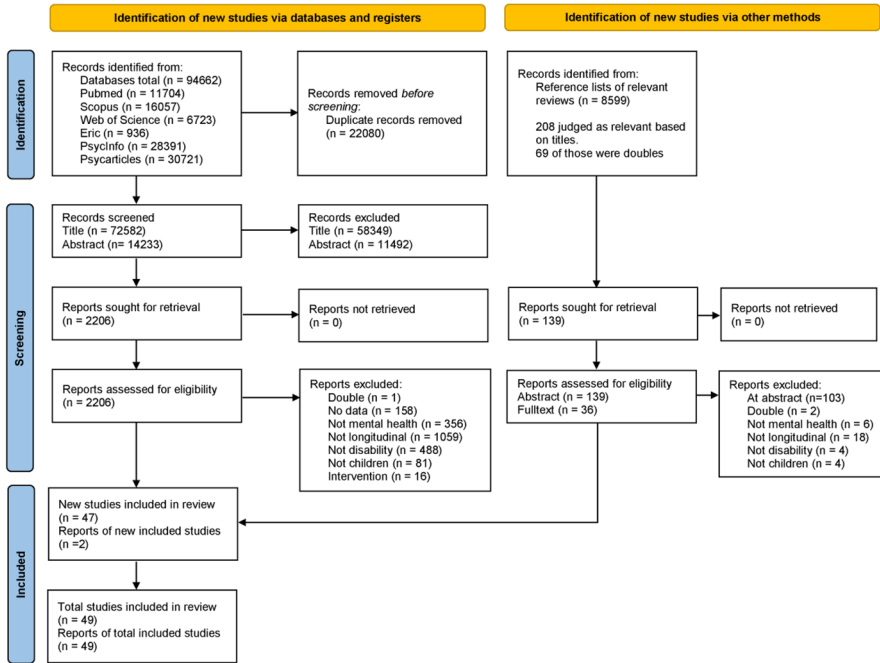


Fig. 1 PRISMA flow diagram (Page et al., 2021) depicting the flow of information in the study including records identified, included, and excluded at the different phases of the study

The most commonly studied populations were children with ADHD and ASD, represented in 12 publications each. Sample sizes ranged from 10 to 722 (total included participants 9,446). Age at baseline ranged from ≤ 1 to 12.3 years, with four publications reporting outcomes starting in the infancy-toddler period, 18 in the preschool period; 18 in middle childhood, and 17 in adolescence (total numbers ≥ 49 , as some publications reported different outcomes at different time points). The follow-up time ranged from 2 to 16.8 years, with occasions of assessment ranging from 3 to 17 times.

The most commonly used assessment tools were the Child Behavior Checklist (CBCL, $n=13$ publications) and the Strengths and Difficulties Questionnaire (SDQ, $n=8$ publications). Most outcomes were collected as proxy-report from parents, and on occasion, teachers. Self-reported outcomes were collected in five studies. In studies reporting results of diagnostic interviews, the informant was either a parent (in two studies) or the child (three), but the information was interpreted by professionals.

Risk of bias

The summary of the risk of bias assessment is displayed in Fig. 2. Almost all studies had some risk of bias, with the most common risks across studies associated with lack of information about the accuracy of measurement of outcomes, identification of confounders, controlling for confounders in analyses, and completeness of follow-up

Table 2 Characteristics of the included studies

Study	Setting		Participants				Follow-up	
	Country	Sampling	Diagnosis	Age ^a	n	Percent females	Length ^a	Occasions
Alsem et al. (2013)	Netherlands	Clinical	CP	2.50	92	41	2	3
Anderson et al. (2011)	USA	Clinical	ASD	9.75	65	11	9	17
Auerbach et al. (2008)	Israel	Community	Dyscalculia	11.10	29	52	6	3
Baribeau et al. (2021)	Canada	Clinical	Dyscalculia-NP	11.10	29	52	6	3
Biederman et al. (1996)	USA	Clinical	ASD	3.34	421	15	7.4	8
Ciciolla et al. (2014)	USA	Clinical/community	ADHD	10.60	128	0	4	3
Colvert et al. (2021)	UK	Community	Delay	3.00	110	33	2	3
Cornish et al. (2012)	UK	Community	ASD	4.00	135	13	9	3
Fielding-Gebhardt et al. (2020)	USA	Community	Fragile X	8.17	48	0	2	3
Flouri et al. (2015)	UK	Community	Fragile X	9.13	55	20	6.8	3
Gotham et al. (2015)	USA	Clinical/community	ASD	3.13	165	22	4	3
Green et al. (2005)	Australia	Clinical	ASD+ADHD	3.11	44	7	4	3
Harvey et al. (2015)	USA	Community	DD	12.30	56	39	6.7	7
Hauser-Cram and Woodman (2016)	USA	Community	DD	3.90	13	23	3	6
Hickey et al. (2020)	USA	Clinical	ADHD	3.68	75	39	3	4
Hogan et al. (2014)	Australia	Community/clinical	DD	3.00	169	46	15	5
Holmbeck et al. (2010)	USA	Community	ASD	9.07	159	13	NR	3
Horbach et al. (2020)	Germany	Clinical/community	Hearing problems	4.75	93	NR	6	4
		Community	Spina bifida	8.34	68	46	6	4
		Community	SLD	6.21	27	33	5	5
		Community	SLD+ADHD	6.21	15	27	5	5
		Clinical/community	ADHD	6.21	13	31	5	5
Hoza et al. (2010)	USA	Clinical/community	ADHD	9.97	513	20	6	4
Hunsche et al. (2020)	Canada	Clinical	ASD	7.70	178	17	3.1	4

Table 2 (continued)

Study	Setting		Participants				Follow-up	
	Country	Sampling	Diagnosis	Age ^a	n	Percent females	Length ^a	Occasions
Kates et al. (2019)	USA	Clinical	22q11.2DS	11.87	87	47	9.3	4
Lahey et al. (2016)	USA	Clinical/community	ADHD	5.24	125	14	12	13
			ADHD	9.24	125	14	8	9
			ADHD	10.24	125	14	7	8
Li et al. (2020)	Netherlands	Clinical	ASD	4.56	59	0	2.1	3
Lindsay et al. (2007)	UK	Clinical/community	SSLD	8.25	69	25	3.8	3
Midouhas et al. (2013)	UK	Community	ASD	3.00	209	17	4	3
Moskowitz et al. (2020)	USA	Community	Fragile X	6.71	153	19	NR	5
Mrug et al. (2012)	USA, Canada	Clinical/community	ADHD	10.35	300	20	6	3
Murray-Close et al. (2010)	USA	Clinical/community	ADHD	10.00	536	19	6	4
Musser et al. (2016)	USA	Community	ADHD	9.53	388	31	2	3
Peveřill et al. (2019)	Canada	Clinical	ASD	3.41	396	16	3.2	4
Rai et al. (2018)	UK	Community	ASD	10.00	96	18	8	6
Rosema et al. (2015)	Australia	Clinical	TBI mild	5.19	13	46	16	5
			TBI moderate	4.89	40	70	16.8	5
			TBI severe	5.09	22	64	16.6	5
Sigafoos (2000)	Australia	Clinical	DD	3.90	13	23	3	6
Sipal et al. (2010)	Netherlands	Clinical	CP	11.23	110	36	3.1	4
St-Clair et al. (2011)	UK	Community	SLI	7.00	234	24	9	4
Steinhausen et al. (2003)	Switzerland	Clinical/community	ADHD	10.20	35	17	2.6	3
Stringer et al. (2020)	UK	Community	ASD	11.60	158	10	11.6	3
Tan et al. (2014)	Netherlands	Clinical	CP 1–4 years	1.50	97	44	3	4
			CP 5–8 years	6.25	116	34	2	3
			CP 9–15 years	11.00	108	37	3	4

Table 2 (continued)

Study	Setting		Participants				Follow-up	
	Country	Sampling	Diagnosis	Age ^a	n	Percent females	Length ^a	Occasions
Vaillancourt et al. (2017)	Canada	Clinical	ASD	3.19	392	16	3.2	4
Van keer et al. (2021)	Netherlands/Belgium	Clinical	SDD	3.10	25	68	2	3
Vaughn et al. (1993)	USA	Community	LD	6.00	10	40	3.2	4
Vaughn and Haager (1994)	USA	Community	LD	6.00	10	40	5	5
Wall et al. (2019)	USA	Clinical/community	Fragile X	0.51	116	25	4.5	8
Wei et al. (2014)	USA	Community	LD	11.59	722	38	3	3
			LD+ADHD	11.63	303	20	3	3
			ADHD+ED	11.17	569	15	3	3
Williams and Sciberras (2016)	Australia	Community	ADHD	0.70 ^b	112	25	6	4
			ADHD-S	0.74	648	36	6	4
Woodman et al. (2015)	USA	Clinical	DD	3.00	176	45	15	5
Woodruff-Borden et al. (2010)	USA	Can't tell	WS	6.67	45	53	4.2	9
Yeates and Taylor (2006)	USA	Clinical	TBI severe	9.90	53	26	3.6	3
			TBI moderate	10.50	56	27	3.6	3
Zendarski et al. (2021)	Australia	Clinical	ADHD	10.70	130	0	3	3

Mean age at the first data collection point was estimated based on information in the article or supplementary material (e.g., the reported mean for the study group and control group combined, school grade) when not specifically reported

Disabilities/diagnoses abbreviations: *22q11.2DS* 22q11.2 deletion syndrome, *ADHD* attention-deficit hyperactivity disorder, *ADHD-S* ADHD symptomatic, *ASD* autism spectrum disorder, *CP* cerebral palsy, *delay* developmental delays, *DD* developmental disabilities, *ED* emotional disturbances, *LD* learning disabilities, *Dyscalculia-NP* nonpersistent dyscalculia, *SDD* significant cognitive and motor developmental delay, *SLI* specific language impairment, *SLD* specific learning disorder, *SSLD* specific speech and language difficulty, *TBI* traumatic brain injury, *WS* Williams syndrome. Other abbreviations: *n* number of participants, *NR* not reported

^aIn years

^bRetrospective analyses of children reported to have ADHD at age 8–9

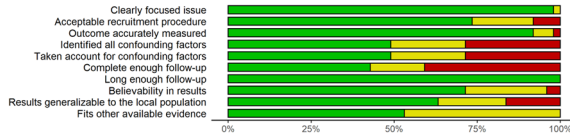


Fig. 2 Summary of the CASP Checklist Risk of Bias Assessments for the included studies (red reflects “high” risk of bias, yellow “can’t tell”, and green “low”)

(i.e., loss to follow up was common). “Addressing a clearly focused issue” was the domain where the risk of bias was lowest. The full list of risk of bias assessments for each domain and included study can be found in Supplementary Fig. 1.

Longitudinal Trajectories of Mental Health Problems

The main purpose, results, and implications of the included studies, as reported by the original study authors, can be found in Supplementary Table 2. Table 3 displays truncated longitudinal outcomes (first, second, third, and last occasion of assessment) for selected mental health problem scales. Data are organized by the mental health problem scale for ease of comparison across studies and populations. The total number of outcomes displayed is 118, which is lower than the sum of all reported outcomes across the included studies. When multiple scales with different degrees of specificity were reported for the same instrument in a study, only the broadest was included. For example, if the total difficulties scale of SDQ was reported together with the four specific subscales that constitute it, only the total difficulties scale was included. Other studies were excluded from the table when it was not possible to calculate the trend. For 45.8% ($n=54$) of these outcomes, the last data point remained within $\pm 10\%$ of the baseline measure. In 31.36% of outcomes ($n=37$), the mental health problem was reduced by more than 10% from the first to the last time point in the trajectory. In 22.88% ($n=27$) of the outcomes, mental health problems increased by 10% or more from the first to the last time point. However, the trend pattern differed when comparing scales measuring aspects of internalizing mental health problems to scales measuring aspects of externalizing mental health problems. In internalizing scales, an upwards trend was seen in 31.71% ($n=13$) of the selected scales when comparing the first and last time points, a stable trend in 46.34% ($n=19$), and a downward trend in 21.95% ($n=9$). In externalizing scales, the trend was increasing in 11.43% ($n=4$), stable in 42.86% ($n=15$), and decreasing in 45.71% ($n=16$). A more comprehensive list of outcomes ($n=148$), arranged alphabetically by study and outcome, can be found in Supplementary Table 3.

Figure 3 displays the variation in longitudinal trajectories measured using the conduct and emotional problems subscales of the SDQ reported in six publications involving five different diagnostic samples. When measured using the SDQ, the conduct problem trajectories of children with ADHD were at a higher level than children with other NDDs such as ASD, specific language impairments (SLI), and specific speech and language disorders (SSLD). The trajectories of children with language-related diagnoses (SLI and SSLD) were found on the opposite side of the

Table 3 Selected mental health problem outcomes of included studies across the first three and the last time points sorted by outcome

Study	Outcome					Trend		
	Diagnosis	Test	Scale	T1	T2		T3	Tlast
Combined scales								
Green et al. (2005)	DD	ABC	Aberrant behaviour	50.92	53.59	55.46	45.77	↘
Sigafoos (2000)	DD	ABC	Aberrant behaviour	50.92	53.59	55.46	45.77	↘
Horbach et al. (2020)	ADHD	CBCL	Emotional + behavioural problems	29.71	41.29	36.00	33.93	→
Midouhas et al. (2013)	ASD	SDQ	Emotional + behavioural problems	14.95	15.53	18.21	18.21	↗
Sipal et al. (2010)	CP	CBCL	Emotional + behavioural problems	34.65	27.56	25.81	25.81	↘
Fielding-Gebhardt et al. (2020)	Fragile X	CBCL	Emotional + behavioural problems	40.22	39.19	33.33	33.33	↘
Horbach et al. (2020)	SLD	CBCL	Emotional + behavioural problems	16.93	19.48	18.92	16.48	→
	SLD + ADHD	CBCL	Emotional + behavioural problems	28.69	36.38	41.46	35.54	↗
St Clair et al. (2011)	SLI	SDQ	Emotional + behavioural problems	11.05	11.79	10.72	9.62	↘
Lindsay et al. (2007)	SSLD	SDQ parent	Emotional + behavioural problems	14.76	14.42	16.23	16.23	→
		SDQ teacher	Emotional + behavioural problems	13.14	12.89	10.53	10.53	↘
Hogan et al. (2014)	Hearing problems	SDQ	Emotional + behavioural problems ^c	40.80	20.30	31.50	29.30	↘
Steinhausen et al. (2003)	ADHD	CBCL	Emotional + behavioural problems ^f	63.30	59.00	56.80	56.80	↘
Hickey et al. (2020)	ASD	TRF	Emotional + behavioural problems ^f	62.03	62.22	62.13	62.13	→
Auerbach et al. (2008)	Dyscalculia	CBCL	Emotional + behavioural problems ^f	54.70	52.70	55.20	55.20	→
Yeates and Taylor (2006)	Dyscalculia-P	CBCL	Emotional + behavioural problems ^f	51.50	47.70	48.10	48.10	→
	TBI moderate	TRF	Emotional + behavioural problems ^f	49.78	49.35	51.11	51.11	→
	TBI severe	TRF	Emotional + behavioural problems ^f	53.23	54.91	57.02	57.02	→
Wei et al. (2014)	ADHD + ED	SSRS	Problem behaviour	15.90	15.21	15.20	15.20	→
	LD	SSRS	Problem behaviour	12.49	12.76	11.98	11.98	→
	LD + ADHD	SSRS	Problem behaviour	13.91	13.44	13.48	13.48	→
Tan et al. (2014)	CP 1–4 y	TAPQOL-PF	Psychological functioning	85.23	83.89	82.55	81.54	→
	CP 5–8 y	TACQOL-PF	Psychological functioning	80.87	80.54	79.87	78.52	→

Table 3 (continued)

Study	Diagnosis	Outcome	Psychological functioning					Trend
			Test	T1	T2	T3	Tlast	
	CP 9–15 y	TACQOL-CF	72.73	73.78	74.83	79.02	→	
Externalizing scales								
Aalsem et al. (2013)	CP	TAPQOL-PF	78.60	71.40	64.30	64.30	↘ ^e	
Hoza et al. (2010)	ADHD	CD checklist	42.20	43.87	43.87	43.62	→	
Murray-Close et al. (2010)	ADHD	CD checklist	1.16	1.16	1.15	1.15	→	
Lahey et al. (2016)	ADHD	DISC self	0.38	0.25	0.14	1.27	↗	
		DISC/DBD parent + teacher	1.58	1.64	1.41	0.95	↘	
Vaughn et al. (1993)	LD	RBPC	49.10	48.90	49.45	46.40	→	
Vaughn and Haager (1994)	LD	RBPC	49.10	48.90	49.45	46.44	→	
Zendarski et al. (2021)	ADHD	SDQ	4.35	3.81	3.71	3.71	↘	
Colvert et al. (2021)	ASD	SDQ	2.91	3.04	2.33	2.33	↘	
Flouri et al. (2015)	ASD	SDQ	3.72	2.57	2.76	2.76	↘	
Stringer et al. (2020)	ASD	SDQ	3.40	1.80	2.10	2.10	↘	
Flouri et al. (2015)	ASD + ADHD	SDQ	4.70	3.93	4.70	4.70	→	
Horbach et al. (2020)	ADHD	CBCL	12.71	16.93	13.64	12.50	→	
Vaillancourt et al. (2017)	ASD	CBCL	17.86	16.37	15.26	14.12	↘	
Li et al. (2020)	ASD	ECI-4	15.92	13.88	13.84	13.84	↘	
Sipal et al. (2010)	CP	CBCL	9.06	6.95	6.49	6.49	↘	
Ciciolla et al. (2014)	Delay	CBCL	17.10	16.00	16.00	16.00	→	
Horbach et al. (2020)	SLD	CBCL	7.00	8.11	7.46	5.07	↘	
	SLD + ADHD	CBCL	10.23	15.08	17.62	13.54	↗	
Peverill et al. (2019)	ASD	CBCL	56.13	54.36	52.88	51.46	→	
Hauser-Cram and Woodman (2016)	DD	CBCL	48.28	48.13	51.01	50.11	→	
Woodman et al. (2015)	DD	CBCL	48.39	48.08	51.00	49.94	→	

Table 3 (continued)

Study	Diagnosis	Outcome		T1	T2	T3	Tlast	Trend
		Test	Scale					
Rosema et al. (2015)	TBI mild	PIC-R/BASC/ABCL	Externalizing problems ^T	61.74	68.31	59.08	48.00	↘
	TBI moderate	PIC-R/BASC/ABCL	Externalizing problems ^T	57.64	59.49	54.36	49.43	↘
Yeates and Taylor (2006)	TBI moderate	TRF	Externalizing problems ^T	51.66	49.56	52.17	52.17	→
Rosema et al. (2015)	TBI severe	PIC-R/BASC/ABCL	Externalizing problems ^T	56.82	59.08	56.21	49.03	↘
Yeates and Taylor (2006)	TBI severe	TRF	Externalizing problems ^T	51.95	54.06	54.71	54.71	→
Anderson et al. (2011)	ASD	ABC	Irritability	11.20	10.60	10.00	8.40	↘
Harvey et al. (2015)	ADHD	DBRS	Oppositional behaviour	1.32	1.46	1.43	1.47	↗
Musser et al. (2016)	ADHD	K-SADS-E	Oppositional behaviour	1.50	1.20	1.20	1.20	↘
		ODD checklist	Oppositional behaviour	1.30	1.00	0.70	0.70	↘
Lahey et al. (2016)	ADHD	DISC/DBD parent + teacher	Oppositional behaviour ^a	4.53	4.34	4.27	1.38	↘
Cornish et al. (2012)	Fragile X	CTRS	Oppositional behaviour ^T	62.64	59.50	62.21	62.21	→
Vaughn et al. (1993)	LD	RBPC	Socialized aggression ^T	48.10	50.15	52.15	49.00	→
Vaughn and Haager (1994)	LD	RBPC	Socialized aggression ^T	48.20	50.15	52.15	49.00	→
Internalizing scales								
Ming et al. (2012)	ADHD	MASC/BAI	Anxiety	2.27	1.91	1.75	1.75	↘
Alsem et al. (2013)	CP	TAPQOL-PF	Anxiety	66.70	66.70	66.70	66.70	→
Lahey et al. (2016)	ADHD	DISC parent	Anxiety ^a	3.09	2.97	3.54	0.77	↘
		DISC self	Anxiety ^a	2.37	2.91	2.37	1.22	↘
Kates et al. (2019)	22q11.2DS	K-SADS-PL/SCID	Anxiety ^d	29.87	28.40	39.47	35.59	↗
Baribeau et al. (2021)	ASD	CBCL	Anxiety ^T	57.10	55.90	55.70	57.50	→
Vaughn et al. (1993)	LD	RBPC	Anxiety ^T	48.10	51.80	52.20	48.30	→
Vaughn and Haager (1994)	LD	RBPC	Anxiety ^T	48.10	51.80	52.20	49.33	→
Hoza et al. (2010)	ADHD	CDI	Depression	6.11	5.49	6.10	7.34	↗

Table 3 (continued)

Study	Diagnosis	Outcome							
		Test	Scale	T1	T2	T3	Tlast	Trend	
Mrug et al. (2012)	ADHD	CDI/BDI	Depression	0.22	0.19	0.22	0.22	0.22	→
Holmbeck et al. (2010)	Spina bifida	CDI	Depression	0.21	0.20	0.18	0.17	0.17	↘
Lahey et al. (2016)	ADHD	DISC parent	Depression ^a	1.42	1.47	1.67	1.33	1.33	→
		DISC self	Depression ^a	4.82	3.92	2.93	1.51	1.51	↘
Rai et al. (2018)	ASD	SMFQ	Depression ^b	35.40	25.50	20.40	25.00	25.00	↘
Zendarski et al. (2021)	ADHD	SDQ	Emotional problems	4.52	3.97	4.48	4.48	4.48	→
Colvert et al. (2021)	ASD	SDQ	Emotional problems	2.21	3.86	3.86	3.86	3.86	↗
Flouri et al. (2015)	ASD	SDQ	Emotional problems	1.99	2.53	3.37	3.37	3.37	↗
Stringer et al. (2020)	ASD	SDQ	Emotional problems	4.60	3.50	3.90	3.90	3.90	↘
Flouri et al. (2015)	ASD + ADHD	SDQ	Emotional problems	1.84	2.69	4.68	4.68	4.68	↗
Horbach et al. (2020)	ADHD	CBCL	Internalizing problems	5.71	8.43	8.14	8.21	8.21	↗
Vaillancourt et al. (2017)	ASD	CBCL	Internalizing problems	16.70	14.49	13.78	12.82	12.82	↘
Li et al. (2020)	ASD	ECI-4	Internalizing problems	5.05	7.61	5.98	5.98	5.98	↗
Sipal et al. (2010)	CP	CBCL	Internalizing problems	9.57	7.79	7.51	7.51	7.51	↘
Ciciolla et al. (2014)	Delay	CBCL	Internalizing problems	12.00	11.70	12.10	12.10	12.10	→
Horbach et al. (2020)	SLD	CBCL	Internalizing problems	3.52	4.56	5.00	4.96	4.96	↗
	SLD + ADHD	CBCL	Internalizing problems	5.85	7.69	8.08	7.77	7.77	↗
Peverill et al. (2019)	ASD	CBCL	Internalizing problems ^f	60.22	58.00	56.91	55.62	55.62	→
Hauser-Cram and Woodman (2016)	DD	CBCL	Internalizing problems ^f	54.99	54.75	52.46	52.78	52.78	→
Woodman et al. (2015)	DD	CBCL	Internalizing problems ^f	55.15	54.69	52.64	52.85	52.85	→
Rosema et al. (2015)	TBI mild	PIC-R/BASC/ABCL	Internalizing problems ^f	56.88	61.85	57.41	52.26	52.26	→
	TBI moderate	PIC-R/BASC/ABCL	Internalizing problems ^f	54.21	55.10	53.86	50.13	50.13	→
Yeates and Taylor (2006)	TBI moderate	TRF	Internalizing problems ^f	48.32	49.59	48.92	48.92	48.92	→

Table 3 (continued)

Study	Diagnosis	Outcome						
		Test	Scale	T1	T2	T3	Tlast	Trend
Rosema et al. (2015)	TBI severe	PIC-R/BASC/ABCL	Internalizing problems ^f	54.92	57.06	55.28	54.75	→
Yeates and Taylor (2006)	TBI severe	TRF	Internalizing problems ^f	51.69	52.43	55.29	55.29	→
Anderson et al. (2011)	ASD	ABC	Lethargy	10.50	9.90	9.40	10.10	→
Kates et al. (2019)	22q11.2DS	K-SADS-PL/SCID	Mood disorders ^d	16.88	17.28	19.74	16.95	→
Li et al. (2020)	ASD	EEQ	Negative emotion	33.14	32.90	33.08	33.08	→
Colvert et al. (2021)	ASD	SDQ	Peer problems	3.68	3.98	4.27	4.27	↗
Flouri et al. (2015)	ASD	SDQ	Peer problems	3.26	3.58	4.20	4.20	↗
Hunsche et al. (2020)	ASD + ADHD	SDQ	Peer problems	2.68	3.48	4.20	4.20	↗
	ASD	CBCL	Suicidal ideation ^f	4.00	2.00	6.00	5.00	↗
Other scales								
Wei et al. (2014)	ADHD + ED	School records	Absences	1.57	1.46	1.46	1.46	→
	LD	School records	Absences	1.22	1.36	1.47	1.47	↗
	LD + ADHD	School records	Absences	0.83	1.05	1.25	1.25	↗
	ADHD + ED	School records	Disciplinary actions	5.69	7.87	4.05	4.05	↘
	LD	School records	Disciplinary actions	0.87	2.11	1.12	1.12	↗
	LD + ADHD	School records	Disciplinary actions	1.74	1.21	1.53	1.53	↘
Williams and Sciberras (2016)	ADHD	ATS-SF IC	Emotional dysregulation	2.50	3.52	3.18	3.50	↗
	ADHD-S	ATS-SF IC	Emotional dysregulation	2.54	3.26	2.87	2.72	→
Wall et al. (2019)	Fragile X	IBQ-R/ECBQ/CBQ	Negative affect	2.64	2.92	3.12	3.81	↗
Kates et al. (2019)	22q11.2DS	K-SADS-PL/SCID	Psychosis ^d	5.19	11.11	13.16	32.20	↗
Wei et al. (2014)	LD	School records	School suspensions	0.29	0.61	0.75	0.75	↗
	LD + ADHD	School records	School suspensions	0.68	0.39	0.80	0.80	↗
Hunsche et al. (2020)	ASD	CBCL	Self-injury ^f	7.00	3.00	5.00	7.00	→
Williams and Sciberras (2016)	ADHD	Single item	Sleep problems	1.81	1.77	1.70	1.71	→

Table 3 (continued)

Study	Diagnosis	Outcome		T1	T2	T3	Tlast	Trend
		Test	Scale					
Peverill et al. (2019)	ADHD-S	Single item	Sleep problems	1.73	1.70	1.55	1.55	↘
Alsem et al. (2013)	ASD	CSHQ	Sleep problems	44.86	44.16	44.24	42.01	→
Wei et al. (2014)	CP	TAPQOL-PF	Sleep problems	81.30	84.40	87.50	87.50	→
	ADHD + ED	School records	Suspensions	2.90	1.25	1.72	1.72	↘

The outcomes reported in the table were selected on the following basis: 1) it was possible to calculate change between first and last time point (i.e., excluding studies not reporting quantitative data for all time points, studies with cumulative scores), 2) it was the most general scale reported for the test (more specific sub-scale scores are only reported in absence of a total scale score). Reported scores are mean raw scores unless marked with a ‘T’ (i.e., T-score) or a specific note. An upwards or downwards pointing arrow under ‘Trend’ indicates that there is a > 10% change between the first and last data points. Disabilities/diagnoses abbreviations: See Table 2 note

Outcome measures abbreviations: *ABC* Aberrant Behavior Checklist, *ABCL* Adult Behavior Checklist, *ATS-SF* IC Australian Temperament Scale—Short Form, Infant and Child Version, *BAI* Beck Anxiety Inventory, *BASC* Behavior Assessment Scale for Children, *BDI* Beck Depression Inventory, *CBCL* Child Behavior Checklist, *CBQ* Children’s Behavior Questionnaire, *CDI* Children’s Depression Inventory, *CSHQ* Children’s Sleep Habits Questionnaire, *CTRS* Connors Teacher Rating Scales—Revised, *DISC* Diagnostic Interview Schedule for Children, *ODD* *checklist* DSM Based Oppositional Defiant Disorder Checklist, *CD checklist* DSM-IV Conduct Disorder Checklist, *DBD* Disruptive Behavior Disorders Rating Scale—DSM-IV Version, *DBRS* Disruptive Behavior Rating Scale, *ECBQ* Early Childhood Behavior Questionnaire, *ECI-4* Early Childhood Inventory—4, *EEQ* Emotion Expression Questionnaire, *IBQ-R* Infant Behavior Questionnaire—Revised, *K-SADS-E* Kiddie Schedule for Affective Disorders and Schizophrenia—Epidemiological, *K-SADS-PL* Kiddie Schedule for Affective Disorders and Schizophrenia for School-Age Children—Present and Lifetime Version, *MAASC* Multidimensional Anxiety Scale for Children, *PIC-R* Personality Inventory for Children—Revised, *RBPC* Revised Behavior Problem Checklist, *RBS-R* Repetitive Behavior Scale—Revised, *SMFQ* Short Mood and Feelings Questionnaire, *SSRS* Social Skills Rating Systems, *SDQ* Strengths and Difficulties Questionnaire, *SCID* Structured Clinical Interview for DSM-IV-TR axis I Disorders, *TRF* Teacher Report Form, *TAPQOL-PF* TNO-AZL Preschool Children Quality of Life Parent Form, *TAPQOL-PF* TNO-AZL Children’s Quality of Life Parent Form, *TACQOL-CF* TNO-AZL Children’s Quality of Life Child Form

^aMean number of symptoms

^bScoring 10 or above (%)

^cSubclinical and clinical (%)

^dProportion (%) meeting diagnostic criteria

^eReversed since a higher score on the TAPQOL-PF indicates less problems

^fProportion (%) endorsing specific item

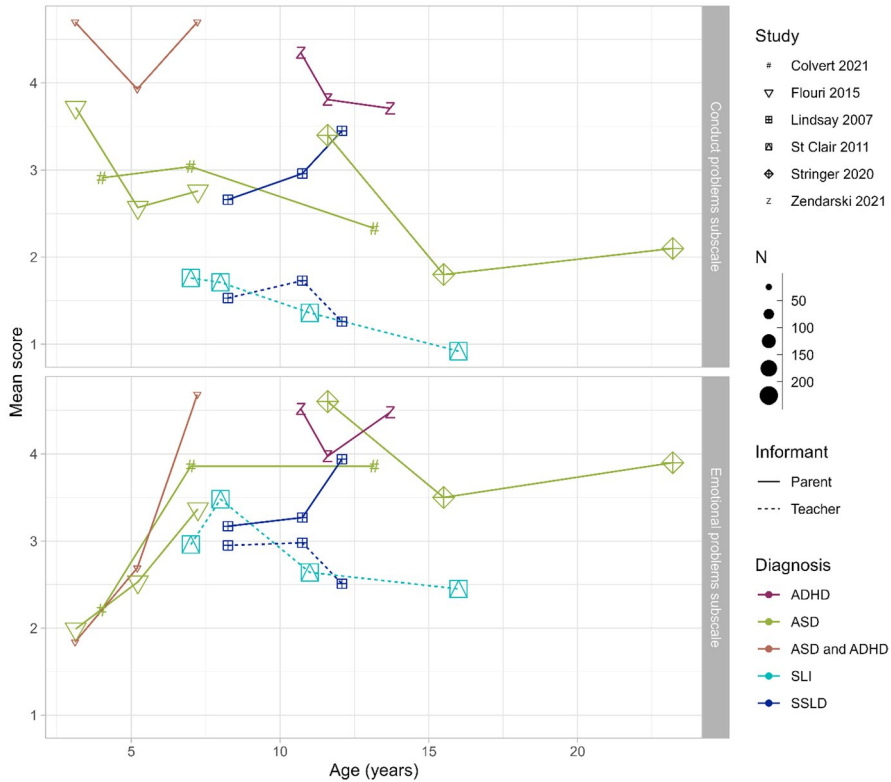


Fig. 3 Longitudinal trajectories for Conduct and Emotional Problems Subscales of the SDQ (panel 1=Conduct problem subscale; panel 2=Emotional problems subscale)

scale, starting and ending at a lower level. The trend was decreasing (> 10%) in six of eight of the trajectories when comparing the first and last data points, stable in one, and decreasing (> 10%) in one. For SDQ-measured emotional problems, there was an increasing (> 10%) trend for four of the included trajectories when comparing the first and last data points, decreasing (> 10%) for three, and stable for one.

Figure 4 displays the variation in longitudinal trajectories measured using the internalizing and externalizing broadband scales of the CBCL reported from 10 publications (nine studies) involving different diagnostic samples. For those studies reporting externalizing problems' raw scores, three of six trajectories ended at a level 10% or more below the starting point, two remained relatively stable, and one ended at a higher level. Two groups of participants (SLD and CP) followed trajectories starting and remaining at lower levels than the trajectories reported in studies involving children with ADHD, ASD, and developmental delay. The externalizing trajectories reported as T-scores (T-scores are relative to the norm data for the test) showed a stable development in six out of seven studies, indicating that the children with different NDDs kept their position relative to the norm group over time in most cases. Raw score internalizing trajectories had an increasing (> 10%) trend when comparing

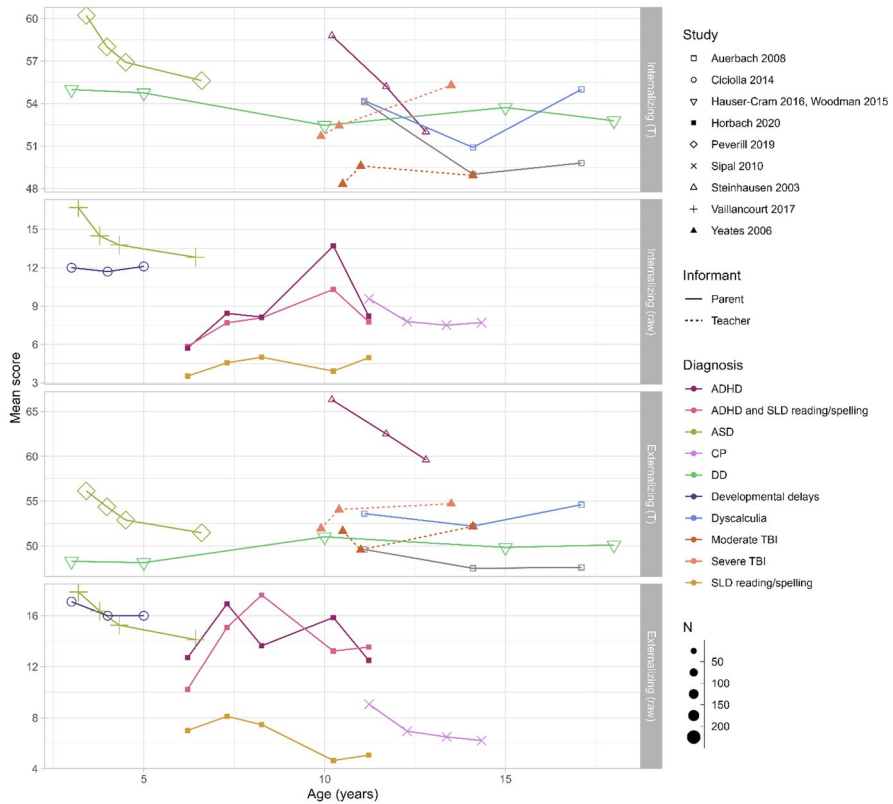


Fig. 4 Longitudinal trajectories of Internalizing and Externalizing Broad-Band Scales measured using the CBCL (panel 1=Internalising T-score; panel 2=Internalising raw score; panel 3=Externalising T-score; panel 4=Externalising raw score)

the first and the last data point in three cases, a decreasing (> 10%) in two cases, and stable in one. T-score trajectories indicated a 10% or more decrease in relation to the norm group in one case and stable trajectories in six cases. Visualizations of additional SDQ and CBCL scale scores are found in Supplementary Figs. 2, 3 and 4.

Variables That Influence Trajectories

There was considerable variation in the approach taken to investigate the role of mediators, moderators, or predictors of mental health problem outcomes across the studies. Twenty-seven studies did not assess any influences on the trajectory. Other studies investigated the effect of one or more variables (range 1 to 13). Table 4 displays the variables investigated and those where changes were found to be statistically significant within studies. Variables identified as significantly influencing trajectories (or outcomes at specific time points) suggest the importance of relationships (i.e., quality of parental relationships; peer relationships); severity of

Table 4 Investigated and significant associations (predictors, moderators, mediators, and correlations) between the longitudinal trajectories of mental health and other variables in the included studies

Study	Scale	Variables associated with mental health problems	
		Investigated	Significant
Baribeau et al. (2021)	Anxiety - CBCL	Sex, family income, IQ, parenting stress, adaptive behaviour, language abilities, insistence on sameness severity	Parenting stress, insistence on sameness severity
Flouri et al. (2015)	Conduct problems - SDQ	Socio-economic disadvantage, age, ADHD, harsh discipline, peer problems, parent-child closeness, parent-child conflict, intact family, maternal psychological distress, sex, ethnicity, maternal education level, stratium (aspect of recruitment design)	ADHD x age (interaction effect), peer problems, parent-child conflict x age (interaction), maternal psychological distress, ethnicity, stratium
	Emotional problems - SDQ	As above	Socio-economic disadvantage x ADHD (interaction effect), peer problems, parent-child closeness, maternal psychological distress
Gotham et al. (2015)	Anxiety - CBCL/ABCL	Emotional control, social affect, restricted/repetitive behaviour, adaptive behaviour (daily living skills, communication, socialization), quality of life (satisfaction, competence, independence, social belonging), wellbeing, family cohesion, family expressiveness, family conflict	Emotional control
	Depression - CBCL/ABCL	As above	Emotional control, satisfaction, communication, social affect
Hauser-Cram and Woodman (2016)	Externalizing problems - CBCL	Socioeconomic status, intellectual disability, negative life events, child impact on the family, maternal depressive symptoms, maternal response to distress	Maternal response to distress, maternal depressive symptoms, child impact on the family

Table 4 (continued)

Study	Scale	Variables associated with mental health problems	
		Investigated	Significant
	Internalizing problems - CBCL	As above	Maternal depressive symptoms, child impact on the family, intellectual disability
Hickey et al. (2020)	Emotional + behavioural problems - TRF	Warmth in the parent-child relationship, criticism in the parent-child relationship	Warmth in the mother-child relationship, criticism in the father-child relationship
Hoza et al. (2010)	Conduct disorder - CD checklist	Self-perceptual bias (social acceptance, behavioural conduct)	Self-perceptual bias (behavioural conduct)
	Depression - CDI	As above	Self-perceptual bias (social acceptance, behavioural conduct)
Hunsche et al. (2020)	Suicidal ideation - CBCL	Adaptive behaviour, baseline internalizing problems, baseline externalizing problems	Adaptive behaviour
	Self-injury - CBCL	Sex, adaptive behaviour, baseline internalizing problems, baseline externalizing problems	Baseline externalizing behaviour
Kates et al. (2019)	Anxiet - K-SADS-PL/SCID	Age, global functioning, ASD diagnosis, IQ, internalizing problems, family conflict	Internalizing problems, family conflict
	Mood disorders - K-SADS-PL/SCID	Age, global functioning, ASD diagnosis, IQ, internalizing problems, externalizing problems, family history of mania or depression	Internalizing problems, global functioning, family history of mania, externalizing problems
	Psychosis - K-SADS-PL/SCID	Age, global functioning, ASD diagnosis, internalizing problems, diagnosis of any anxiety disorder, verbal IQ, baseline prodromal symptoms, T1-T3 change in verbal IQ	Internalizing problems, global functioning, verbal IQ, baseline prodromal symptoms, ASD diagnosis

Table 4 (continued)

Study	Scale	Variables associated with mental health problems	
		Investigated	Significant
Lahey et al. (2016)	Anxiety - DISC parent	Longitudinal age, family income, sex, intelligence, baseline inattention symptoms, baseline hyperactivity-impulsivity symptoms, baseline depression symptoms, baseline anxiety symptoms, baseline CD symptoms, baseline ODD symptoms	Sex, baseline depression symptoms, baseline anxiety symptoms, longitudinal age
	Depression - DISC parent	As above	Sex, baseline CD symptoms, baseline depression symptoms, baseline anxiety symptoms, longitudinal age
	Conduct disorder - DISC/DBD parent + teacher	As above	Family income, baseline CD symptoms, baseline anxiety symptoms, longitudinal age
	Oppositional behaviour - DISC/DBD parent + teacher	As above	Sex, family income, baseline ODD symptoms, baseline anxiety symptoms, longitudinal age
	Anxiety - DISC self	As above	Intelligence, baseline anxiety symptoms, longitudinal age
Li et al. (2020)	Conduct disorder - DISC self	As above	Baseline CD symptoms, longitudinal age
	Depression - DISC self	As above	Intelligence, longitudinal age
	Externalizing problems - ECI-4	Emotion control, emotion recognition, emotion vocabulary	Emotion control, group x emotion vocabulary (interaction effect)
	Internalizing problems - ECI-4	As above	Emotion control, emotion recognition

Table 4 (continued)

Study	Scale	Variables associated with mental health problems	
		Investigated	Significant
Midouhas et al. (2013)	Emotional + behavioural problems - SDQ	Socioeconomic disadvantage, maternal warmth, maternal involvement, home organization, age, sex, low birthweight (<2.5 kilos), verbal cognitive ability, maternal education	Maternal warmth, maternal education, verbal cognitive ability ^a
Moskowitz et al. (2020)	Self-injurious behaviour - RBS-R	Age, sex, nonverbal IQ	Age, sex, age x sex (interaction effect)
Musser et al. (2016)	Compulsive behaviour - RBS-R Oppositional behaviour - ODD checklist	As above Parental expressed emotion, parental criticism, parental emotional over-involvement, hyperactive symptoms, inattentive symptoms, income, IQ	Nonverbal IQ Parental criticism, income, IQ, hyperactive symptoms
Rai et al. (2018)	Depression - SMFQ	Bullying	Bullying
Sigafoos (2000)	Aberrant behaviour - ABC	Receptive language age, expressive language age, combined language age	Receptive language age, expressive language age, combined language age
Sipal et al. (2010)	Emotional + behavioural problems - CBCL Externalizing problems - CBCL Internalizing problems - CBCL	Situational stress/support, relational stress/support, motor ability, gender, age As above As above	Situational stress/support, relational stress/support, age Situational stress/support, relational stress/support, motor ability, gender Situational stress/support, relational stress/support
St Clair et al. (2011)	Emotional + behavioural problems - SDQ	Expressive language, receptive language, pragmatic language, reading accuracy	Expressive language, pragmatic language

Table 4 (continued)

Study	Variables associated with mental health problems		
	Scale	Investigated	Significant
Stringer et al. (2020)	Conduct problems - SDQ	Infant and toddler development, language estimate (nonverbal/phrase/fluent), severity of autistic traits, adaptive functioning, household parental education, parental mental health problems, neighbourhood deprivation, school placement, informant (usually mother) affective symptoms	Infant and toddler development, adaptive functioning, language estimate, neighbourhood deprivation
Tan et al. (2014)	Emotional problems - SDQ	As above	Severity of autistic traits, language estimate, parental education
	Psychological functioning - TACQOL-CF	Type of CP, gross motor function, intellectual disability	None
	Psychological functioning - TACQOL-PF	As above	As above
	Psychological functioning - TAPQOL-PF	As above	As above
Vaillancourt et al. (2017)	Externalizing problems - CBCL	ASD symptom severity, intellectual ability, family income, sex	Family income, intellectual ability
	Internalizing problems - CBCL	As above	Sex, family income
Wall et al. (2019)	Negative affect - IBQ-R/ECBQ/CBQ	Sex	Sex
Woodman et al. (2015)	Externalizing problems - CBCL	Parental stress	Parental stress
	Internalizing problems - CBCL	As above	As above

Disabilities/diagnoses abbreviations: see Table 2 note. Outcome measures abbreviations: see Table 3 note

symptoms and/or baseline mental health problems; child characteristics (i.e., biological sex, intellectual impairment, child's communication or language skills); parental health and the socio-economic resources of the family.

Discussion

Synthesis of Findings

The 49 publications reported in this review suggest a growing interest in longitudinal mental health outcomes for those with NDD. The considerable heterogeneity in the populations studied, concepts and scales applied, the length of follow-up, and other methodological aspects risk making any summary of the results simplistic. Nonetheless, some patterns stand out in answer to our research question. First, mental health problems in children with NDD are often stable over time. In almost half of the longitudinal studies included in the present review, change was smaller than 10% when comparing the first and last data points. Second, when a change occurred, it was more likely to be in the form of an upward trajectory for internalizing problems, mirroring findings in children with typical development (Costello et al., 2011), and a downward trajectory for many outcomes that could be described as externalizing behaviours. Third, outcomes measured using the two most commonly applied scales (CBCL and SDQ), show that children with ADHD and ASD tend to start at higher levels of internalizing and externalizing problems, than other diagnostic groups.

There was considerable overlap of studies across the included 49 publications because they were longitudinal designs and because of researchers' interest in disseminating new knowledge as it is learned. This overlap needs to be considered in relation to the overall volume of research available on the topic. The population included in the research is also important to consider: it was more common that children with ADHD or ASD were the populations of interest than those with primary physical disorders, such as CP or SB. One possible explanation for this difference is that it mirrors the prevalence of different NDDs in the population (McIntyre et al., 2022; Polanczyk et al., 2007; Zeidan et al., 2022), another is that ADHD and ASD, unlike CP and SB, are classified as mental disorders. The scarcity of studies about children with CP and SB could also be due to fewer problems in these groups, making them less motivating to investigate. However, this might be an artefact of clinician and researcher focus on the primary movement and sensory disorders, with a relatively more recent awareness of mental health problems in this group and subsequent lack of longitudinal studies to track impact (Downs et al., 2018; Whitney et al., 2019a, b). In addition, most studies have focused on middle childhood – ages 5 to 15 years, with only a few studies beginning to follow children in earlier childhood or later adolescence. Longitudinal follow-up across the childhood years requires valid reliable measures that cross the age groups.

Summary of Confidence in the Available Evidence

Confidence in the findings of this review is influenced by the volume, quality, and consistency of the evidence available. The inclusion of 49 studies involving 9,446 participants indicates a reasonable volume of evidence when considering NDD overall. We used the CASP tool for cohort studies to evaluate the quality of the included longitudinal studies with 10 of 14 individual items reported in Fig. 2 and Supplementary Fig. 1. We excluded item 3, as none of the included studies was interventional, and item 8, 'precision', as interpretation across the range of methods was problematic. Items 7 (results) and 12 (implications) are reported in Supplementary Table 2 but are not included in the risk of bias summary. Of the included studies, only one (Peveerill et al., 2019) rated positively on all ten risk of bias domains. The remaining studies carry some risk of bias (bias scores ranged from 1 to 6 per study). The most common concerns related to incomplete follow-up and a lack of control for potentially confounding factors on outcomes.

Incomplete follow-up is common in longitudinal research, and the longer the desired follow-up, the more difficult it is to maintain the sample's engagement. Strategies for sustaining participant involvement are important, to build trust in the findings as the direction of influence from loss to follow-up may be difficult to predict. We included studies with at least three occasions of measurement over two or more years, as the minimum requirement for a longitudinal study, thus we considered risk of bias related to the length of follow-up in this review to be low. Without at least three measures it is not possible to understand the shape of change (Ployhart & Vandenberg, 2010), and with only three data points (as occurred in 26 [53%] studies), peaks or troughs in measurement are difficult to interpret. The findings of this review suggest that repeated follow-up of mental health problems should continue for longer than two years to obtain accurate outcomes and not miss a critical time point for the trajectory, something that is important for our long-term goal of informing future interventions.

Another serious concern in longitudinal research is the inadequate consideration of potentially confounding factors. In this review, only 22 (45%) studies identified, and analytically controlled for, or explored, potentially confounding or explanatory factors. It is unlikely that all children will experience the same pattern of outcome and identifying factors that could be modified (e.g., parental stress) and sub-groups who may require greater support (e.g., those with co-morbid diagnoses) can only be done if there are well-considered hypotheses that are tested over time.

Variables Explored as Predictors, Moderators, or Mediators in Comparison to the Literature on Children Without Disabilities

Few of the included studies reported information on specific variables mediating or moderating the direction of trajectories over time. A more common design was to include baseline variables predicting outcomes at one or more time points or trajectory group membership. No study investigated the influence of the child's participation on mental health problem outcomes. Many of the factors found to be associated with the longitudinal trajectories of mental health problems in children with NDDs

in the present study are similar or identical to factors identified in studies with typically developing children. For example, family socio-economic status has repeatedly been linked to mental health problems in typically developing children (Peverill et al., 2021). Among the studies included in the current review, a significant association was identified between baseline family income and child conduct disorder and oppositional behaviour in children with ADHD (Lahey et al., 2016), parental education and emotional problems in children with ASD (Stringer et al., 2020), and family income at baseline and heightened levels of externalizing and internalizing problems in children with ASD (Vaillancourt et al., 2017). Female biological sex was also associated with higher rates of internalizing symptoms in ASD (Vaillancourt et al., 2017) and ADHD (Lahey et al., 2016), as expected from findings in typically developing populations (Costello et al., 2003). Another example is maternal depressive symptoms, which have been linked to internalizing and externalizing symptoms in typically developing children in earlier research (Goodman et al., 2011), and to children with developmental disabilities in the current review (Hauser-Cram & Woodman, 2016).

Some factors identified in the present study are more closely related to the NDD itself, e.g., the severity of insistence of sameness or other autistic traits in children with ASD, the presence of comorbid conditions (ID and/or ASD), and other aspects of child functioning (e.g., communicative functioning and/or adaptive behaviour). Such child-related factors are of interest when it comes to identifying sub-groups where the risk for mental health problems is higher but may be relatively static and thus not ideal as a target for interventions at the individual level. However, other identified factors, such as parenting stress, aspects of the child-parent relationship, or peer relationships could be more dynamic and therefore feasible as targets for intervention. In addition to identifying single or, multiple factors influencing mental health problem outcomes in children with NDDs, knowledge about the cumulative effects of risk and protective factors is needed. Wille et al. (2008) highlight the importance of identifying cumulative risks, as these increase the rates of mental health problems, but it is also important to note that the effects of the risks are moderated by increasing child, family, and social resources.

Measures and Respondents

The two most frequently applied scales in the present review, SDQ and CBCL, are both instruments primarily aimed at screening for emotional and behavioural problems. As such they do not clearly distinguish between problems that could be primarily related to an NDD, or as part of the condition (such as hyperactivity), and theoretically separate issues, e.g., anxiety or depression. For more specific subscales, such as those capturing emotional difficulties, the risk of confusion may be negligible. However, when applying the broad-band internalizing and externalizing scales as was often the case in the studies included in this review, there is a risk of confusion between NDD-related difficulties and comorbid problems; for example, communication problems and the peer-problem scale in the SDQ. Consequently, it is not always possible to determine to what degree a change in a longitudinal trajectory reflects a change in a core NDD-related difficulty and/or a separate emotional

problem. Items that confound NDD characteristics with mental health problems may also lead to evidence of stronger stability in the problems assessed, which may partly explain the stability seen in the current review. The results of the current study indicate that this problem of conceptual clarity is present in the field but does not clearly describe the extent. Future research will need to further investigate the extent of this conceptual overlap and whether the measures taken to address it are sufficient. Notably, neither SDQ nor CBCL was specifically developed for use with children with an NDD and their application in these groups has been debated. For example, internal consistency is only modest for children with ID (similar to children without ID) in the SDQ (Emerson, 2005), and in those with ID, the factor structure may deviate from the expected three or five-factor solution (Haynes et al., 2013).

The present review demonstrates that the assessment of mental health problems in children with an NDD is still highly dependent on parent ratings. Solely measuring profoundly subjective experiences from the perspective of another person is, however, not without problems. Correlations between teacher, parent and child-rated mental health problems are often weak (De Los Reyes et al., 2015). A similar pattern can also be seen in the few studies with multi-informant ratings included in the present review. In the field of quality of life measurement in individuals with ID, an international panel of experts stated some 20 years ago that “proxy measurement [...] is not valid as an indication of a person’s perception of his or her life” (Schalock et al., 2002, p. 462), adding that it should always be clearly stated when measurement reflects the perspective of another person than the participant for whom the outcome is measured. Even though young age and/or level of cognitive impairment sets limits for when self-rating is possible, such factors do not explain the lack of a child perspective in many of the studies included in the current review. The consequence of over-relying on parent observations is that overt behaviours visible in some contexts (e.g., home) are over-emphasized in comparison to covert behaviours and other contexts (e.g., among peers).

Strengths and Limitations

The heterogeneity of the results in the present study is a logical consequence of our broad inclusion criteria. For example, the broad definition of mental health problems led to the inclusion of outcomes such as school suspension and absences (Wei et al., 2014). Although such outcomes may not be considered mental health problems in a more narrow sense, previous research has demonstrated that children who refuse to go to school have a higher risk of psychiatric disorders than other children (Egger et al., 2003). While it might be appealing to limit the scope of this review to a more narrow definition of mental health problems (e.g., only internalizing problems), one or fewer diagnostic groups, or parts of the developmental period, this would also entail the risk of missing patterns that span these elements. The presented study deliberately sought to identify such patterns on an overarching level. The low sensitivity (included records divided by the total amount of records) for the searches indicates that a narrower search strategy could have been used, but also implies that we can be relatively sure that most relevant records have been found.

Because of our broad interest, we also retrieved a very large number of records from the searches. To address this volume of work, we involved a large team of reviewers. There is some risk of inconsistency in the selection processes because of the large team, however, varied pairs of reviewers undertook these steps, following written guidelines, and discrepancies were discussed and resolved.

Another limitation is that only studies written in English were included in the review. There is a risk that studies written in other languages and cultural contexts could be systematically different to some degree, thereby introducing some level of bias in the results.

Assessing risk of bias in these studies was limited by the lack of an empirically supported tool specifically for longitudinal research. To increase the consistency in our approach, we developed additional explanatory criteria, and only two authors independently undertook this aspect. Even so, most papers required discussion of at least some criteria to come to consensus decisions.

Our approach to synthesizing the findings may be critiqued for the decision to include only the first three and last data points to interpret the overall direction of the trajectory for each paper. While the figures provide additional information for two measures, this approach did not allow us to analyze the shape of trajectories over time. Of course, all data points in longitudinal research provide key information about how development changes over time and needs to be considered to avoid assumptions of linearity or a simplified form of trajectory. By including only four data points, the additional information contained in 21 of the included studies (where data were collected between five and 17 times) is glossed over. Those with particular interest, are of course able to review the original studies.

Implications of the Findings for Practice and Research

It is clearly important to conduct longitudinal outcomes research, particularly through the childhood years and into adulthood, to understand the course of important developmental outcomes. The variation in approaches to longitudinal studies included in this review, suggests that encouraging researchers to publish their longitudinal study protocols would be of benefit to the field. Protocol publications require research teams to be explicit, and thoughtful, about their theories, hypotheses, and methods, and they benefit from peer review. In addition, future systematic reviews can take advantage of published protocols when interpreting interim publications.

Our review highlights the need for more careful consideration of measures of mental health problems to ensure that the chosen scales do not confound the NDD diagnosis with additional mental health concerns. Self-report of subjectively experienced phenomena is needed, and this requires us to design and validate measures that support children and adolescents with varying communicative and cognitive support needs to report their experiences.

Since many of the factors found to be associated with the mental health problems trajectories were the same as for typically developing children, it is reasonable to think that many interventions designed for typically developing children targeting these factors would be relevant for children with NDD as well. In that case,

the question could be more a matter of cognitive and physical accessibility of those treatments rather than of the fundamental theoretical assumptions of the interventions. It is, however, possible that such interventions could become more effective by adding components specifically targeting risk factors that are unique to children with NDD or factors for which exposure is higher than for typically developing children. Parental stress and parental mental health are two examples of modifiable risk factors that were identified in our review. These risk factors are likely to be higher for children with NDD than for typically developing children, but they are also identified in the literature in typically developing children (Lee, 2013; Miodrag & Hodapp, 2010). Incorporating elements aiming at reducing these issues, or reducing the overall number of risk factors (Wille et al., 2008), could be hypothesized to lead to effects on mental health in the children as well, based on the findings in the present review. The Rusk et al. (2018) synergistic change model takes a dynamic systems-based approach to address sustained changes in mental health/wellbeing, suggesting that lasting change (improved mental health) is more likely if reinforcing (synergistic) changes occur across multiple domains of positive functioning: goals and habits; emotions; attention and awareness; virtues and relationships; and comprehension and coping. It is also important to note that there may be additional factors that are uniquely or unusually strongly associated with mental health problems in children with NDD that research to date has failed to identify, such as participation in important everyday activities. Knowledge of general and NDD-unique risk and protective factors is needed to leverage positive change.

Conclusions

We conducted a systematic review of longitudinal trajectories of mental health problems in children with NDDs. Our findings suggest that the most commonly used tools are screening measures of problems and that trajectories are predominantly stable or demonstrate reducing problems. However, there is an important lack of self-report in the available data and an over-emphasis on following the mental health problem outcomes of children with particular NDD diagnoses. The measures used are not specifically designed to assess mental health problems in children with NDDs. Some expressions of mental health issues can be confounded with characteristics of impairment, e.g. hyperactivity, communication problems, and peer problems.

The factors found to be associated with the identified mental health problems were similar to factors found in typically developing children. Many of these factors are static and difficult to change on an individual level. To inform the design of targeted interventions, evidence over time about the emergence and resolution of modifiable risk factors is needed.

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Code and Data Availability All data that was extracted from the included studies and a reproducible version of the manuscript, including the code, are available at <https://osf.io/wh3q4/>.

Compliance with Ethical Standards

Conflicts of Interest The authors have no competing interests to declare that are relevant to the content of this article.

Ethical Approval Since the study did not involve human or non-human participation, ethical approval was not required.

Informed Consent The collection of informed consent was not applicable since the study did not involve human participants.

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