									METHODS OF DATA COLLECTION																
									CLINICIAN EVALUATION - DEVELOPMENTAL FUNCTIONING					PARTICIPANT PROVIDED: Personal or Self Report											
NAME OF STUDY	Principal Investigator	Contact person	website	Country	sample size (total for all) ASD, DD, CO	Male	Female	Age of assessment	ASD diagnosis		Other assessments			Questionnaire Collection		Medical Information		Biospecimens Collected	Biological analyses available	Other	Special Population?			Abstract (of entire stud	Notes
									methods of DX (ADOS, ADI, SCQ, etc)		non dx asd measurements			Demographics, SES, diet, etc.		area of functioning	Self report or medical record	Type			Race	High-Risk I.E. Siblings	Medical/Genetic Exposure I.E. Epilepsy, Premature Infants		
									NAME		*Name*	*Individual w*	*Parent/Sibling*	*Type of data*	*Who*										
ADDM	Matt Maenner , PhD	Jon Baio (xzb1@cdc.gov)	https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm	USA	ASD TOTAL: 5108 (Birth year 2008)	4:1 ratio of males vs females		Record based reviews of 8 year olds	Documentation in record		IQ			Demographics	Based on school/parent records	None		None	None					The ADDM Network currently tracks ASD in multiple US communities (c	
					Additional data from earlier birth dates available				ASD diagnosis: record must contain a diagnosis c		Definition of an intellectual disabsility														
Autism Brain Net	David Amaral, PhD	Ikue Nagakura (Inagakura@ucdavis.edu)	www.autismbrainnet.org	USA	192 postmortem brains PLUS the autism tissue program legacy tissue.	UNK	UNK	Phenotypic collected at various ages or postmortem	ADI		Educational and Medical records	X		Demographics	Familyreport/Records	Whatever medical information is available		Frozen and fixed brain tissues	None		Any		Idiopathic autism, duq15, other rare genetic mutations	For more information go to www.autismbrainnet.org	
											SRS			Medical History	Familyreport/Records										
Autism Sequencing Consortium	Joe Buxbaum, PhD	Steve Guter (sguter@uic.edu)	https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/study.cgi?study_id=phs000298.v4.p3	International	n=12,772	Estimation: 7,800	Estimation: 5,000	All ages	ADI-R		Vineland, SRS, IQ (measure used varies by site)			Demographics/Medical History	Family Report/Records	Medical Records	Family Pedrigree	Blood	whole exome sequencing		All races		All	Research during the past decade has seen significant progress in the understanding of the genetic architecture of autism spectrum	http://genome.emory.edu/ASC/wp-content/uploads/2019/11/ASC_Neuron_December-2012.
			https://genome.emory.edu/ASC/						ADOS																
									SCQ																
Autism Treatment Network	UNK	Angie Fedele (afedele@autismspeaks.org)	https://www.autismspeaks.org/autism-treatment-network-atn	USA	UNK	UNK	UNK	UNK	ADOS	WISC-IV	IQ BINET			AGRE Race and Ethnicity		Parent Baseline		Blood	UNK	UNK	UNK	UNK	UNK	The Autism Treatment Network (ATN) is a collaboration of Autism Spea	
									ADI-R	WPPSI	CBCL					Medical History form									
									DAS-II	CELF-5	Pediatric Quality of Life Inventory														
									MULLEN																
									WASI-II																
									BAYLEY SCALES																
BABY SIBLINGS	Greg Young, PhD	Greg Young dryoungucdavis@edu	https://www.babysiblingsresearchconso	International	n=5000	UNK	UNK	2 months-4 year	Mullen	1 - 36 months	MacArthur Communicative Developme		x	Parent Concerns	Parent	Head circumference		Saliva, DNA on limited sub-sample	DNA available on subset	MRI, EEG, Eye tracking on a subset	All	Yes	Siblings	The Baby Siblings Research Consortium (BSRC) is a network of over 40	
									ADOS	18-36 months	SCQ		x												
									Clinical Best Estimate diagnosis, following BSRC		SRS (Encouraged)														
									ADI-R	36 months	Vineland (Encouraged)	x	x												
											DSM interview		x												
											Treatment History Questionnaire		x												
CHARGE	Irva Hertz-Picciotto, Rebecca Schmidt, Deborah Bennett, Cheryl Walker	Yunin Ludena yludena@ucdavis.edu	beincharge.ucdavis.edu	USA	1,730 (ASD:868; DD:330; Control:532) and growing	1,374	356	2 years - 5yrs 1mo	For those with prior ASD Dx or high score on the		SRS, MSEL, VABS, Aberrant Behavior Checklist.	All children	Parent SRS	Demographics (questions	mother & child; father (demographics and occupation only)	Medical Records:	self-report of maternal prior health; conditions and medications during pregnancy; child's health conditions, growth, medications, hospitalizations, etc.	blood & urine from child (primary), mother, father, and sibling	immune markers (cytokines, chemokines), nutrients, SNP array, gene expression, sequencing, DNA methylation, copy number variants, persistent organic pollutants , Hg, metabolomics, lipids,	Dust samples	all. Approximately 54% are white; non-Hisp		population-based samples, which includes preterm infants, children with seizure disorders, and various genetic disorders, such as Down Syndrome and others.	The CHARGE Study is a population-based case-control investigation of	
											SCQ	only those with no previous ASD dx.		FFQ/diet	child (primary)	Family history		hair from chid (primarey & mom							
											ABC	Y						saliva if no blood from child. Also from father							
																		teeth from child (primary)							
Dup15q Syndrome and Angelman Syndrome	UNK	Anne Wheeler (acwheeler@rti.org)	https://www.dup15q.org/	USA	UNK	UNK	UNK	UNK	UNK	UNK	UNK			Sleep Habbits		UNK		UNK	Whole genome sequencing				Autism, epilepsy and other neurological issues like dystonia and dsyautonomia	Through our work to raise awareness and promote research into chron	
														Demographics											
														Seizure Questions											
FORWARD: Fragile X Registry with Accessible Resaerch Database (FORWARD)	Milen Velinov	Amie Milunovich (amie@fragilex.org)	http://forwardfx.org/	USA	1,594 FXS participants with clinician form data; of these, autism (either current or past) has been reported for 792 (49.7%).			All Ages	BSID3 (RUSH, CINCINNATI, & COLORADO ONLY)	CELF (RUSH, CINCINNATI, & COLORADO ONLY)	SCQ (All 25 clinics)					PedsQL (RUSH, CINCINNATI, & COLORADO ONLY)		UNK					Intellectual disability and autism spectrum disorder	The purpose of FORWARD is to contribute to the understanding of the	
									FORWARD CLINICIAN REPORT		SRS (All 25 clinics)					FORWARD PARENT REPORT									
											ABC-FX (All 25 clinics)														
											W-ADL (all 25 clincs)														
											SB5 (RUSH, CINCINNATI, & COLORADO ONLY)														
											RBANS (RUSH, CINCINNATI, &														
											VINELAND (RUSH, CINCINNATI, & COLORADO ONLY)														
											RBS-R														
											ERP														
											CCS														
											ASIEP3 (COLORADO ONLY)														
											FXS Short Motor Battery														
											PEDI-CAT														
											LENA														
											Fit-Bit Activity Monitoring														
MARBLES	Rebecca J. Schmidt, PhD, Sally Ozonoff, PhD, Deborah Bennett, PhD, Irva Hertz-Picciotto, PhD	Daniel Young dthyoung@ucdavis.edu	marbles.ucdavis.edu	USA	n=319 (ASD: 75, Other:45, TD: 199) and growing	182	137	6mo, 12mo, 24mo, 36mo	Mullen, ADOS, ADI		SRS	Clinical confirmation of proband ASD diagnosis	SRS	Demographics	Mother, Father, younger sibling, older ASD sibling	Medical Records		blood, placenta, breast milk	Genetics, metabolomics, expression, DNA methylation, cytokines, urinary pesticides, some nutrient measures, EDCs		all	yes		Pregnancy study with focus on identifying early biomarkers of ASD risk and environmental exposures that modify risk.	
											SQC			FFQ/diet	Mother, younger sibling, older ASD sibling	Family history		hiar, urine,fecal							
											CBCL			Supplement use	Mother, younger sibling, older ASD sibling			saliva							
														Environmental Exposures	Mother, younger sibling										
MSSNG (DB6)	Dean Hartley, PhD and Steve Scherer, P	Dean Hartley/Morgan (dean.hartley@autismspeaks.org)	https://research.mss.ng/	International	n=11,364	7,107	4,074	All Ages	ADOS		VINELAND	X	X	Unknown ask PI		Medical Records	Family pedigree	blood and lymphocytes (Saliva, White blood cell, cell line)	Whole genome sequencing		All races	Yes	Families with ASD	We are performing whole-genome sequencing of families with autism	
									ADI		RBS-R														
											SRC														
											SCQ														
											Child Behavior Checklist														
											Aberrant Behavior Checklis														
National Survey of Children's Health	Michael D Kogan, PhD	https://mchb.hrsa.gov/data/national-su	https://mchb.hrsa.gov/data/national-surveys/questionnaires-datasets-supporting-documents	USA	Total: 43 021. ASD (Unweighted): 1131 No. With ASD (Weighted) in Thousands: 1529	Unknown	Unknown	AGES: 0-17	Questions asked about ASD, previous autism dia		Topical Questionnaire 0-5		X	Household Screener	Parents	Birth Characterist	Self Report	None	None	None	All			To estimate the national prevalence of parent-reported autism spectrum disorder (ASD) diagnosis among US	Kogan MD, Vladutiu CJ, Schieve LA, et al. The Prevalence of Parent-
											Topical Questionnaire 6-11		X	Sociodemographic	Parents										
											Topical Questionnaire 7-12		X												
											Questions about medical diagnosis, ps		X												
Nurse Health Study II	Walter Willett and Heather Eliassen	Kristen Lyall (Email: kld98@drexel.edu), Marc Weisskopf (mweissko@hsph.harvard.edu	https://www.nurseshealthstudy.org	USA	116,430 female nurses (estimated 600 with ASD); the nested case-control study was conducted based on 2005 ASD reporting in ~500 cases and ~2500 controls	83% of cases and 51% controls		0-Adulthood	Maternal Report		SRS conducted within nested case-control study			Demographics	Mostly Caucasian	Nurse Health que	Self report	In subset but overlap with ASD n may be small	Potentially		All			Data indicate that the prevalence of a	https://pubmed.ncbi.nlm.nih.gov/28525627/?from_term=Lyall+K+autism+Nurses+Health&from_sort=date&fro
									ADI-R subsample of 50					birth year		Child health ques	Self report								https://pubmed.ncbi.nlm.nih.g
														community income		Gestational diabe	Self report								
														prenatal exposure to hazardous air pollutants		Preeclampsia	Self report								
														NHSII questionnaire		Smoking during p	Self report								
														Maternal/Paternal age at birth		Premature birth	Self report								
														Income	mostly mid-to-high										https://pubmed.ncbi.nlm.nih.g
														Education	nurse-educated mothers										
Phelan-McDermid Syndrome Foundation	Megan O'Boyle	Megan O'Boyle (meganoboyle@gmail.com)	https://www.pmsf.org/	USA	1479 Total, 327 diagnosed with autism/autism like features, 179 say yes to ADD/ADHD diagnosis	628	744	Varies			Developmental Questionnaire		x	Sleep status		Seizure questions	Self report	Collected blood and skin at 2 family conferences. One collection is owned by the NIMH (at Rutgers) and the other at CIRM			All			Phelan-McDermid Syndrome(PMS) is a rare genetic condition caused b	
											Behavior/Cognitive		x	Gastrointestinal		Speech status	Self report								
											Communication		x	Neonatal questions		Psychiatric quest	Self report								
											Fine Motor		x			Swalowing and Ch	Self report								
											Puberty Questionnaire		x			Allergy questions	Self report								
											Self-help questionnaire		x			Lymphatics	Self report								
											Social-Emotional Development		x			Immunology	Self report								
																Orthopedic									
																Cardiovascular	Self report								
																Endocrine	Self report								
																Vision /hearing/M	Self report								
																Renal/Kidney issu	Self report								
																Skin	Self report								
																Weight loss/Urina	Self report								
SEED (study to explore early development)	Centers for Disease Control	Karen Pazol (ijb2@cdc.gov)	https://www.cdc.gov/ncbddd/autism/seed.html	USA	PHASE 1: 2313 (ASD 613, DD 883, POP 817)			2-5 years	ADOS		SCQ		X			Paternal medical history form	Self-report	PHASE 1: Blood and saliva collected; GWAS and DNA methylation data generated for ASD and POP children and mothers			All races		All	The Study to Explore Early Development (SEED), a multisite investigat	
					PHASE 2: 2028 (ASD 651, DD 709, POP 668)				ADI-R		EDQ		X	3-day diet diary	Filled out by parent for child	Child Sleep Habits	Self report	PHASE 2: Blood and saliva collected; no genetic or epigenetic data have been processed to date.							
					PHASE 3: 1624 (ASD 421, DD 590, POP 571)				OARS		SRS		X	Paternal occupational history form	Self report	Gastrointestinal	Self report	PHASE 3: Blood and saliva collected during first part of study, but blood collection was discontinued; saliva collection was ongoing until activities had to be halted due COVID-19; no genetic or epigenetic data have been processed.							
									MULLEN		VINELAND			Caregiver interview	Done by biological Mother	Maternal medical history	Sef report								
											CBCL		X			Autoimmune disease survey	Self report								
											Carey Temperament Scale		X			preconceptionc, prenatal, and labor/delivery periods	Medical record								
																neonatal and pediatric3	Medical record								
																7-day stool diary	Self report								
																Services and treatments questionnaire	Self report								
Simons Searchlight	Wendy Chung, MD, PhD	Jennifer Tjernagel	https://www.sfari.org/resource/simons-searchlight/	USA	Over 1,500 individuals w/rare disorders	UNK	UNK	All ages	ADI-R	ADOS	Vineland	X	X	Feeding Questionnaire	Completed by parent	Medical History (phone call)		Blood drawn, Skin biopsy, Saliva/cheek cells		FMRI, MEG, MRI	All races (must speak English)		All	We describe a project aimed at studying a large number of individuals variations (deletion or duplication of segment 16p11.2) that increase (ASD) and other developmental disorders. The genetics-first approach	
									ADOS-T	DAS-II	CCC-2	X	X	EAH	Completed by parent	Education									
									MULLEN	WASI	MCDI		X	LOC	Parent/Siblings	Medication interview									
									DKEF	Purdue Pegboard	ABCL		X	Pediatric Sleep	Completed by parent	Background History Form									
									Movement ABC-2	CELF-4	CBCL					HWHC Form									
									CASL	CTOPP	DISC		X												
									WIAT III		SCL-90-R	X													
											BAPQ	X	X												
											BSIQ		X												
											PSI		X												
											SCQ		X												
											SRS		X												
											SRS-ARV		X												
											Mother Other Pregnancy		X												
											Edinburgh Handedness	X													
											HWHC	X													
											ARI (ONLINE)	X	X												
											ABCL (ONLINE)		X												
											BSIQ (ONLINE)		X												
											BAPQ (ONLINE)		X												
											CBCL (ONLINE)		X												
											CRI-R (ONLINE)		X												
											GO-LIFE (ONLINE)	X	X												
											GO-LIFE (CHILD)		X												
											MCHAT		X												
											Seizure Survey	X	X												
											TRF and SRS		Teacher												
Simons Simplex Collection	12 sites Pis (full list: https://www.sfari.	Casey White-Lehman	https://www.sfari.org/resource/si	USA	2,644 simplex families, each with one child with ASD and unaffected parents and siblings			Proband: 4 years - 17.11 year	ADI-R		ABC	x		Background history form	Completed by parent on self, proband, sib	Parent Substance	Completed by parent on self	Blood drawn (Whole blood DNA, LCL DNA, Saliva	DNA, LCLs, iPSCs, Plasma may be available for c	WES, WGS genetic data a	All races	Unaffected sibling	Exclusion criteria can be found in SSC Resea	The Simons Simplex Collection (SSC) is a core project and resource of	
									ADOS		ABCL		x	Family pedigree form	Completed by parent on proband	Height, Weight, H	Direct asessment of parents, proband, and sibling			A subset of approximately 1,500 families are enrolled in the SSC Reg			https://simonsfoundation.s3.amazonaws.com/share/Resources/SSC_Researcher_Welcome_Packet.pdf		
									Diagnosis summary form		BAPQ		x	TRF	Completed by teacher on proband, sibling	Medical History In	Completed by parent on self, proband, and sibling								
									DAS-II		CBCL	x	x	C-TRF	Completed by teacher on proband, sibling	Temperature	Direct assessment of proband								
									Purdue Peg Board		DCDQ	x				Treatment Histor	Completed by parent on proband								
									WASI		FHI-I		x			Family physical/d	Direct asessment of parents, proband, and sibling								
									WISC-IV		CTOPP-NR	x													
									SCQ-L, SCQ-C		PPVT-4	x													
											Raven's Standard Progress	x													
											RBS-R	x													
											SRS-ARV		x												
											SRS - Parent report	x	x												
											SRS - Teacher report	x	x												
											VABS-II	x	x												
SPARK	Wendy Chung, MD, PhD	Amy Daniels	https://www.sfari.org/spark-phenotypic-measures/	USA	N=230,936 & more than 90,000 individuals with ASD	ASD: 69170	ASD: 21745	All Ages	SCQ		VINELAND	X	X	Demographics	Family Members	Medical History	Self-Report	Saliva	Whole exome sequencing		All races	No	All	SPARK (Simons Foundation Powering Autism Research for Knowledge)	
									Caregiver report		SCQ		X												
											RBS-R	X													
											CBCL	X	X												
											SRS-2	X	X												
Tuberous Sclerosis Alliance	UNK	Jo Ann Nakagawa (jnakagawa@tsalliance.org)	https://www.tsalliance.org/	USA	UNK	UNK	UNK	UNK	UNK		UNK			Patient / Parent report		Epilepsy surgery Questionnaire		DNA, PLASMA, REMNANT TISSUE FROM SURGERIES	UNK	UNK	UNK	UNK	UNK	The TS Alliance endeavors to stimulate, support and coordinate resear	
														Demographics		Epilepsy Questionnaire									