

ATN Registry Instruments. Version Date 07.20.09				ATN-CRT-07-02						
DOMAIN	ASSESSMENT & VERSION	COPYRIGHT / CUSTOM Ver	ADMIN TIME (MIN)	PRIMARY SOURCE OF INFO	AGE RANGE	SECTIONS COLLECTED	SYSTEM	ITEMS ENTERED INTO DATABASE	REFERENCES	
Screening	Inclusion/Exclusion	5.1 May 8, 09	10	Coordinator	All	All	Advantage EDC	All		
DIAGNOSTIC	Autism Diagnostic Observation Schedule (ADOS), all 4 modules	WPS No. W-365A(4), ©1999, 2001	60	Child/Clinician Interview	All	All for the appropriate module	ISAAC	All (algorithm scoring)	Lord C, Risi S, Lambrecht L et al (2000). The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. J Autism Dev Disord. Jun;30(3):205-23; Lord C, Rutter M, Goode S. et al (1989). Autism diagnostic observation schedule: a standardized observation of communicative and social behavior. J Autism Dev Disord. Jun;19(2):185-212.	
DIAGNOSTIC	DSM-IV Symptom Checklist	3.0 April 17, 09	10	Clinician Checklist	All	All	Advantage EDC	All	American Psychiatric Association (2000) Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR, 4th edition (DSM-IV)	
Demographic	Demographic	7.0 April 17, 09	5	Parent	All	All	Advantage EDC	All		
Demographic	Demographic (Annual)	3.0 April 17, 09	5	Parent	All	All	Advantage EDC	All		
MEDICAL & HISTORY	Developmental and Medical History	3.0 April 17, 09	TBD	Parent Questionnaire/ Clinician review	All	All	Advantage EDC	All	AGRE Further Assessment Survey Modules I and II, START Medical History, CPEA, AGRE Birth and Medical History	
MEDICAL	Diagnosis and Treatment (Visit) Form- Parent Report	4.0 April 17, 09	TBD	Parent Checklist	All	All	Advantage EDC	All		
MEDICAL	Diagnosis and Treatment (Visit) Form- Clinician Report	4.1 July 17, 09	TBD	Clinician Checklist	All	All	Advantage EDC	All		
MEDICAL	Targeted Referral Form	2.1 July 17, 09	TBD	Medical Record	All	All	Advantage EDC	All		
MEDICAL	Lab & Imaging Form	1.0 April 17, 09	TBD	Medical Record	All	All	Advantage EDC	All		
PHYSICAL	Dysmorphology Exam	0.9 Aug 29, 2008	TBD	Clinical Exam	All	All	Advantage EDC	All		
PHYSICAL	Physical and Neurological Exam	3.0 April 17, 09	TBD	Clinical Exam	All	All	Advantage EDC	All		
COGNITIVE	Mullen Scales of Early Learning	AGS-#11152, ©1995	60	Child/Clinician Interview	Birth to 68 months [5 years 8 months] and children who cannot basal on the Stanford Binet	All	ISAAC	Summary Scores	Mullen, E. M. (1995). Mullen Scales of Early Learning (AGS ed.). Circle Pines, MN: American Guidance Service Inc.	
COGNITIVE	Bayley Scales of Infant Development, 3rd Edition	Psych Corp. ©2005	30 - 60 minutes depending on the child	Child/Clinician Interview	One to 42 months of age	All	ISAAC	All	Greenspan, S, Wieder, S. Engaging Autism, First Edition (Perseus Publishing, Cambridge, MA, 2006);	
COGNITIVE	Stanford-Binet, 5th edition ABBREVIATED VERSION	Riverside Publishing ©2003	30	Child/Clinician Interview	2 to 85+ years	Fluid Reasoning & Knowledge	ISAAC	Summary Scores	Roid, G. H. Stanford Binet Intelligence Scales, Fifth Edition (Riverside Publishing, Itasca, IL, 2003); Roid, G. H. Stanford Binet Intelligence Scales, Fifth Edition, Examiner's Manual (Riverside Publishing, Itasca, IL, 2003); Roid, G. H. Stanford Binet Intelligence Scales, Fifth Edition, Technical Manual (Riverside Publishing, Itasca, IL, 2003).	

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ADAPTIVE	Vineland Adaptive Behavior Scales - II (Survey Interview Form)	AGS-#31013, ©2005	45	Parent/Clinician Interview	All	All but Maladaptive Behavior	ISAAC	Summary Scores	Sparrow, S. S., Balla, D. & Cicchetti, D. V. Vineland Adaptive Behavior Scales (Survey) (American Guidance Service, Circle Pines, MN, 1984); Sparrow, S. S. & Cicchetti, D. V. Diagnostic uses of the Vineland Adaptive Behavior Scales. J Pediatr Psychol 10, 215-25 (1985); Sparrow, S. S., Cicchetti, D. V. & Balla, D. The Vineland-II Adaptive Behavior Scales (Survey Interview Form) (American Guidance Service, Circle Pines, MN, 2005).
ADAPTIVE	Vineland Adaptive Behavior Scales - II (Parent/Caregiver Rating Form)	AGS-#31013, ©2005	45	Parent Questionnaire	All	All but Maladaptive Behavior	ISAAC	Summary Scores	Sparrow, S. S., Balla, D. & Cicchetti, D. V. Vineland Adaptive Behavior Scales (Survey) (American Guidance Service, Circle Pines, MN, 1984); Sparrow, S. S. & Cicchetti, D. V. Diagnostic uses of the Vineland Adaptive Behavior Scales. J Pediatr Psychol 10, 215-25 (1985); Sparrow, S. S., Cicchetti, D. V. & Balla, D. The Vineland-II Adaptive Behavior Scales (Survey Interview Form) (American Guidance Service, Circle Pines, MN, 2005).
PSYCHIATRIC COMORBIDITY	Child Behavior Checklist (CBCL) Ages 1.5-5	ASEBA 7-28-00 Edition 601, ©2000	30	Parent Questionnaire	1.5-5	All	ISAAC	Summary Scores	Achenbach, T. M. & Ruffle, T. M. The Child Behavior Checklist and related forms for assessing behavioral/emotional problems and competencies. Pediatr Rev 21, 265-71 (2000); Cohen, N. J., Gottlieb, H., Kershner, J. & Wehrspann, W. Concurrent validity of the internalizing and externalizing profile patterns of the Achenbach Child Behavior Checklist. J Consult Clin Psychol 53, 724-8 (1985).
PSYCHIATRIC COMORBIDITY	Child Behavior Checklist (CBCL) Ages 6-18	ASEBA 6-1-01 Edition 201, ©2001	30	Parent Questionnaire	6-18	All	ISAAC	Summary Scores	Achenbach, T. M. & Ruffle, T. M. The Child Behavior Checklist and related forms for assessing behavioral/emotional problems and competencies. Pediatr Rev 21, 265-71 (2000); Cohen, N. J., Gottlieb, H., Kershner, J. & Wehrspann, W. Concurrent validity of the internalizing and externalizing profile patterns of the Achenbach Child Behavior Checklist. J Consult Clin Psychol 53, 724-8 (1985).
PSYCHO-SOCIAL	Pediatric Quality of Life (PedsQL), 4 versions, based on AGE	JW Varni ©1998/ Mapi Research Trust	10	Parent Questionnaire	2-4; 5-7; 8-12; 13-18	All for the appropriate version	ISAAC	All	Varni, J. W., Seid, M. & Kurtin, P. S. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care 39, 800-12 (2001).
SENSORY	Sensory Profile, short form	Psych Corp. ©1999	15	Parent questionnaire	3 to 10 years	All	ISAAC	All	Dunn W. Performance of typical children on the Sensory Profile: an item analysis. (1994). Am J Occup Ther. Nov-Dec;48(11):967-74; Kientz MA, Dunn W. (1997). A comparison of the performance of children with and without autism on the Sensory Profile. Am J Occup Ther. Jul-Aug;51(7):530-7.
GI	GI Symptom Inventory Questionnaire	3.0 April 17, 09	TBD	Parent Questionnaire	All	All	Advantage EDC	All	
GI	GI Symptom Inventory Questionnaire Annual Update	3.0 April 17, 09	TBD	Parent Questionnaire	All	All	Advantage EDC	All	
SLEEP	Child Sleep Habits Questionnaire (CSHQ), Abbreviated 33 item version	2.0 April 17, 09	10	Parent Questionnaire	4-12	All	Advantage EDC	All	Owens, J. A., Spirito, A. & McGuinn, M. The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children. Sleep 23, 1043-51 (2000).
EXPERIENCE OF CARE	Satisfaction Survey	1.0 April 17, 09	TBD	Parent Questionnaire	All	All	Advantage EDC	All	

These clinical protocols have been developed through contributions of numerous clinical experts using funding provided by in part or in whole by Autism Speaks and by institutions cooperating in the Autism Treatment Network, and have been subjected to peer review under the auspices of Autism Speaks and the Autism Treatment Network. The clinical protocols are intended to assist clinical professionals in the application of their professional judgment in the diagnosis of and identification of treatment modalities for autism spectrum disorders. Autism Speaks is not a licensed provider of health care services and these protocols are not a substitute for the treating physician's clinical judgment. Autism Speaks and the Autism Treatment Network have served solely as a funding source for and as the convener of independent clinicians, scientists and researchers who have contributed to the development of these protocols.

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