ICHOM
International Consortium for
Health Outcomes Measurement

Autism Spectrum Disorder
DATA COLLECTION
REFERENCE GUIDE

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Measuring

results

that matter

Autism Spectrum

Disorders

(ASD)

AUTISM SPECTRUM DISORDERS (ASD)

We are thrilled that you are interested in measuring outcomes for your patients with Autism Spectrum Disorders according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. A comprehensive data dictionary, as well as scoring guides for patient-reported outcomes, is included in the appendix.

Our aim is to make Standard Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. In order to have a guide from which we can benchmark outcomes, we require feedback from initial implementation efforts. As such, this Reference Guide may undergo revisions on a regular basis. If you have any suggestions or would like to provide feedback, please contact info@ichom.org.

Working Group Members for Autism Spectrum Disorders

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Autism Spectrum Disorders in partnership with ICHOM, under the leadership of Dr. Ivy Chong, ICHOM Standard Set Chair. The work was supported by Dr. Tim Kutta, ICHOM Research Fellow, Dr Zofia Das-Gupta, ICHOM Director, Andria Joseph, Alexandria Silkworth, ICHOM Project Manager(s), and Christiana Ilesanmi, ICHOM Research Associate.

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Supporting Organizations

The Autism Spectrum Disorders Standard Set is made possible only through the support of the following organizations.

Thank You.

Scope of Autism Spectrum Disorders Standard Set

For Autism Spectrum Disorders, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Autism Spectrum Disorders
Populations	18 months – Adulthood
Treatment approaches	All treatment approaches
Excluded population	< 18 months[1]
Excluded conditions	NA

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[1] Deficits in the core domains of ASD typically present between 12 and 24 months of age. Evidence suggests that ASD can be reliably diagnosed in infants as young as 18 months of age and the American Academy of Pediatrics recommends ASD-specific screening at 18 and 24 months of age.

ICHOM Autism Spectrum Disorder (ASD) Track Information

Leading researchers, psychologists, behavioural analysts, and service user representatives from across Europe, the Americas, and Asia joined forces to create and develop the first international standard for measuring treatment outcomes for autism spectrum disorders of children and adults over the age of 18 months old.

This standard set has two tracks in order to facilitate the implementation of the set, in countries that use specific tools in existing reimbursement models and for those without.

Both tracks measure the same outcomes and they are risk adjusted with the same factors however:
- o **Track A** recommends tools with cost associated with them to match existing tools in the current reimbursement models in North America
- o **Track B** recommends tools that are free or have a low cost, and can be used in any healthcare system

ICHOM Standard Set for Autism Spectrum Disorder

Case-Mix Variables

Patient Population	Measure	Definition	Timing	Data Source	Track
Demographic factors				*organization can add local flavor to these variables*	
All patients	Age	Indicate the patient's age	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Gender identity and sex	How do you or your child identify their gender? What is you or your child's sex?	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Work status	What is your work status?	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	*Ethnicity	The cultural ethnicity of the person that they most closely identify with	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	*Race	The biological race of the person	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	*Living Arrangements	The living arrangements of the person	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Level of Inclusion at School	Does your child feel accepted in school?	Baseline	Patient-reported, Carer, parent	Both Tracks
Clinical factors					
All patients	Comorbidities SACQ	Indicate whether the patient has a documented history of any of the following comorbidities …	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Hospitalization	All admissions to hospital & Total number of days spent in the past 12 months	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Sleep Medication	Number of medications prescribed	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Family History of Developmental Disorders	Does your family have a history of mental or neurological disorders? If so, then which ones?	Baseline	Patient-reported, Carer, parent	Both Tracks
All patients	Intellectual Impairment	Has your child been previously diagnosed with an intellectual impairment?	Baseline	Has your child been previously diagnosed with an intellectual impairment?	Both Tracks
All patients	Symptom Severity	Have you or your child previously received a diagnosis of ASD that categorized the severity of the ASD symptoms? If so, then what was that level of severity?	Baseline	Have you or your child previously received a diagnosis of ASD that categorized the severity of the ASD symptoms? If so, then what was that level of severity?	Both Tracks

Outcomes

Patient Population	Outcome	Definition	Timing	Data Source
Core Symptoms (Defined according to DSM-5 and ICD-11)				
All patients (2 and older)	Restricted and Repetitive Behaviors	1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases). 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).	Diagnosis, Start of Care 1 year, Post care	Clinician reported
All patients	Social Communication	1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions. 2. Deficits in expressive (e.g., the inability to effectively communicate one's wants and needs and expressively identify vocabulary) and receptive language behaviors (e.g., the inability to independently follow instructions or receptively identify vocabulary). 3. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.	Diagnosis, Start of Care 1 year, Post care	Clinician reported
Daily Functioning				
All patients	Daily Functioning Skills	Adaptive behavior assessed across five domains (i.e., communication, daily living skills, socialization, motor skills, and maladaptive behavior)	Diagnosis, Start of Care 1 year, Post care	Clinician reported
All patients (6-21 years)	Leisure	Participation (i.e. diversity, intensity, where, with whom, enjoyment and preference) and two categories of recreation and leisure activities: (i) formal and informal activities; and (ii) five types of activities (recreational, active physical, social, skill-based and self-improvement)	Diagnosis, Start of Care 1 year, Post care	Clinician reported
Accessibility & Supports				

All patients (1-18 years)	Quality of Life	There is no universal definition, but Felce and Perry's (1995) review identified five core domains: physical well-being, material well-being, social well-being, emotional well-being, and development and activity.	Diagnosis, Start of Care 1 year, Post care	Clinician reported
All patients (12 and older)	Family Functioning	Family functioning can be measured across seven domains: problem solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning	Post care	Self-reported
Other				
All patients (6-18 years)	Anxiety	Here anxiety is defined within the context of internalizing behaviors. Internalizing behaviors reflect mood disturbance, including anxiety, depression, and social withdrawal. Anxiety symptoms may present in a variety of ways including a specific phobia, OCD, social anxiety, separation anxiety, or intense levels of distress related to changes in their routines or environment	Diagnosis, Start of Care 1 year, Post care	Patient Reported
All patients (0-3 years)	Sleep	Here sleep is defined as sleep patterns, parents' perception of their child's sleep habits, and sleep-related behaviors	Start of Treatment, Post treatment	Patient Reported
All patients	Emotion Regulation	A person's ability to effectively manage and respond to an emotional experience.	Start of Treatment, Post treatment	Patient Reported

'Nice to Have' Outcomes

The '*Nice to Have Outcomes'* are outcomes that the Working Group decided was important to capture however the group was unable to recommend a tool for the outcomes due to either
 a) a gap in the literature due to a lack of validated tools in the ASD space
  b) the current existing tools in the literature were not feasible as they were either burdensome and therefore would not be feasible to implement.
The Working Group recommends that the list of "nice to have" outcomes will be reviewed in the future and then added to the core set once the appropriate tool is developed.

Patient Population	Outcome	Definitions
All patients (2 and older)	Social Impairments	Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
	Occupation	Occupational performance in all areas of life, including self-care, leisure and productivity
	Psychopathology	A broad term that can refer to the manifestation of behaviors and experiences which may be indicative of mental illness or psychological impairment, such as abnormal, maladaptive behavior or mental activity
	Suicidal Ideation	Can distinguish between wishing that one was dead (i.e., passive ideation) and actively considering suicide (i.e., active ideation)

Follow-Up Algorithm

The following algorithm illustrates when the Standard Set variable should be collected from patients and clinicians.
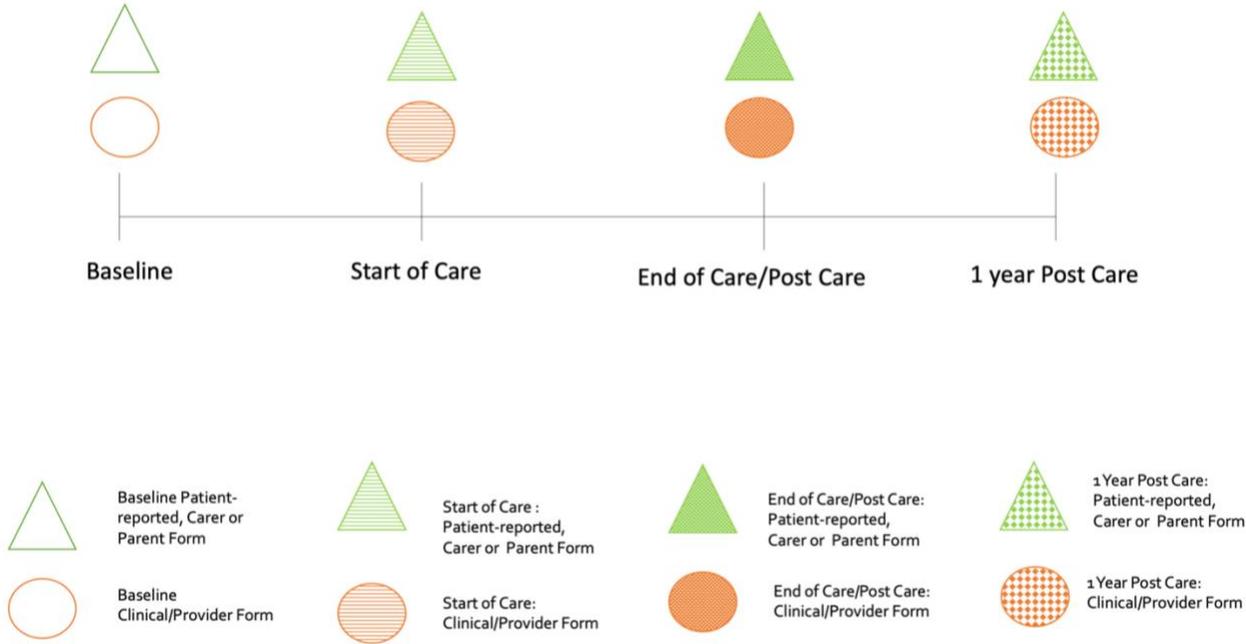
Collecting Outcome Measures

Track	Autism Spectrum Disorder measures	Licensing Information	Scoring Information
Both Tracks	**The Repetitive Behavior Scale- Revised (RBS-R)**	No information available regarding licensing. Free for all to use.	Contact authors for more information: Neurodevelopmental Disorders Research Center, University of North Carolina at Chapel Hill, CB# 3367, Chapel Hill, NC 27599-3367, USA. kristen_lam@med.unc.edu
Both Tracks	**Child and Family Quality of Life (CFQL-2)**	No information available regarding licensing. Free for all to use.	Contact authors for more information: Thomas W Frazier, PhD, Center for Autism (CR11), The Cleveland Clinic, 9500 Euclid Avenue, Cleveland, OH 44195, Phone: (216) 448-6037 gro.fcc@2teizarf
Both Tracks	**Vineland Behavior Scales (VABS)**	Must be purchased for use.	Click here for training and purchasing information: https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAdaptiveBehaviour/vineland-3/vineland-adaptive-behavior-scales-third-edition-vineland-3.aspx
Both Tracks (Track B: can be used as a supplementary PROM if extra measurement is needed)	**Child Behaviour Checklist (CBCL)**	Must be purchased for use.	Click here for training and purchasing information: https://www.apa.org/depression-guideline/child-behavior-checklist.pdf
Track B	**Patient Health Questionniare-2 (PHQ-2)**	Freely available online. License not needed	Click here for more information on the tool: www.phqscreeners.com
Track B	**Family Adaptability and Cohesion Evaluation Scale (FACES)**	Freely available online. License not needed.	Click here for a pdf version of the questionnaire https://ccie.ucf.edu/wp-content/uploads/sites/12/2018/07/FACES-IV-Questionnaire.pdf Scoring and administration information: https://acuonline.instructure.com/courses/1486/files/219284/download?verifier=rSU7tNXYzFOLIOGNn8p46nj377lnpRTXiZQtwgbE&wrap=1.

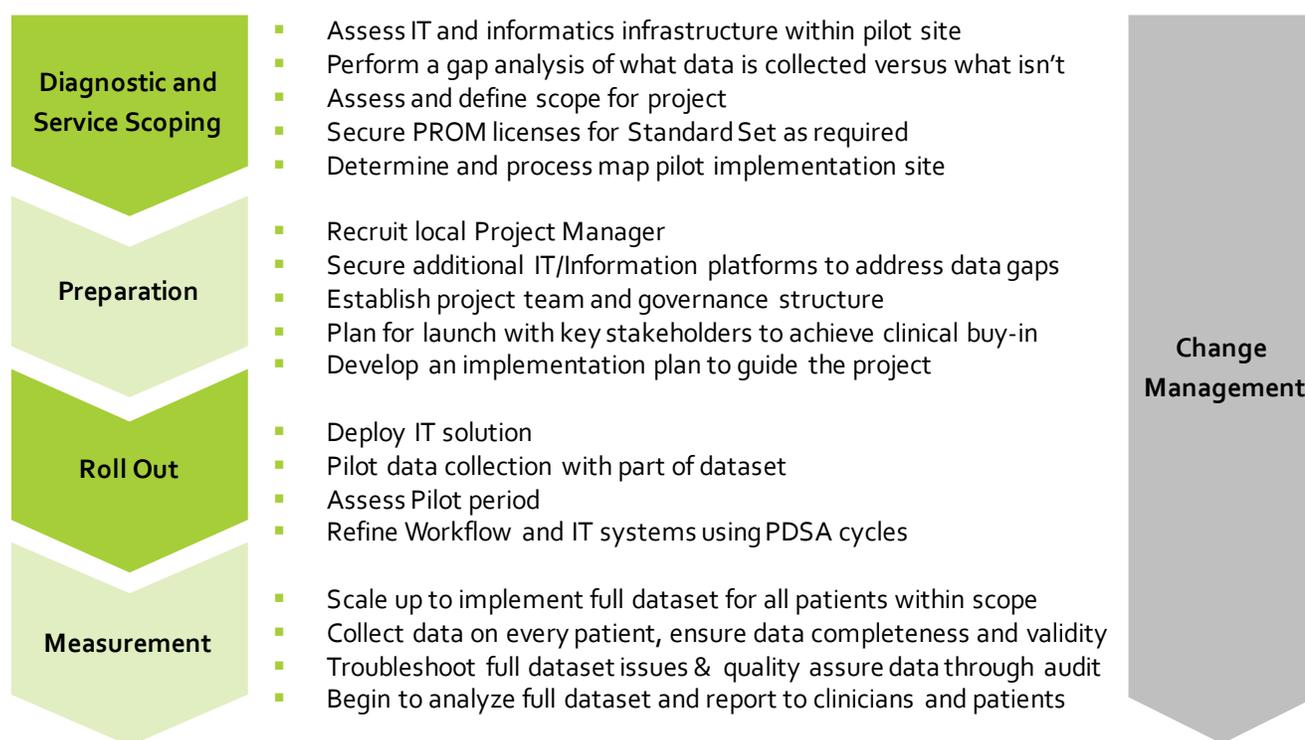| Track B	Empathy Quotient (EQ)	Freely available online. License not needed.	Click here for online version of the tool, that can score answers for respondents: https://psychology-tools.com/test/empathy-quotient To download the tool in multiple languages, please click here: https://www.autismresearchcentre.com/tests/empathy-quotient-eq-for-adults/
Track B	Paediatric Sleep Questionnaire (PSQ)	Freely available online. License not needed.	Click here to access the pdf version of the questionnaire: https://bayclinicpediatrics.net/getattachment/27a261cc-b54b-413e-b22c-e3f36a37aa2f/Pediatric-Sleep-Questionnaire.aspx
Track A	Brief Infant Sleep Questionnaire (BISQ)	Publicly available and free to use	The tool is featured at the bottom of the original authors article: https://pediatrics.aappublications.org/content/pediatrics/113/6/e570.full.pdf
Track A	Preferences for Activities for Children (PAC)	Must be purchased for use.	More information available here: https://www.canchild.ca/en/resources/43-measures-of-children-s-participation-and-enjoyment-cape-pac
Track A	The Positive and Negative Affect Schedule (PANAS/PANAS- Children)	No licensing information available (free to use).	Scoring information available here: https://www.hsph.harvard.edu/health-happiness/positive-and-negative-affect-schedule/
Track A	The McMaster Family Assessment Device (FAD)	**Licensing fees are determined on the basis of the information provided on the registration form.**	Click here for training
Track A	Social Responsiveness Scale (SRS)	Must be purchased for use.	Click here for training and purchasing information: https://www.pearsonclinical.co.uk/Psychology/ChildMentalHealth/ChildAutisticSpectrumDisorders/srs-2/social-responsiveness-scale-second-edition.aspx

The Growing ICHOM Community

ICHOM International Consortium for Health Outcomes Measurement

There is a growing community of healthcare providers implementing the ICHOM Standard Sets. To support your organization in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centered outcomes. For further information or to enquire about Implementation support offered by ICHOM, please contact the Implementation team: info@ichom.org.

Implementation framework:
The framework below, outlines the structured process to guide the implementation of an ICHOM Standard Set at your organization. Typically, an implementation project takes 9 months to complete.

Diagnostic and Service Scoping
- Assess IT and informatics infrastructure within pilot site
- Perform a gap analysis of what data is collected versus what isn't
- Assess and define scope for project
- Secure PROM licenses for Standard Set as required
- Determine and process map pilot implementation site

Preparation
- Recruit local Project Manager
- Secure additional IT/Information platforms to address data gaps
- Establish project team and governance structure
- Plan for launch with key stakeholders to achieve clinical buy-in
- Develop an implementation plan to guide the project

Roll Out
- Deploy IT solution
- Pilot data collection with part of dataset
- Assess Pilot period
- Refine Workflow and IT systems using PDSA cycles

Measurement
- Scale up to implement full dataset for all patients within scope
- Collect data on every patient, ensure data completeness and validity
- Troubleshoot full dataset issues & quality assure data through audit
- Begin to analyze full dataset and report to clinicians and patients

Change Management

ICHOM is also able to support organizations with a variety of support models:

1. Capacity building – direct advisory support
2. Community models – supporting a community of providers in outcomes adoption and innovation
3. Education – workshops and short courses regarding Value Based Healthcare and implementation skills

Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, we recommend following the ten steps outlined below:*[1]

Step 1	Preparation	Initial work carried out before the translation work begins
Step 2	Forward Translation	Translation of the original language, also called source, version of the instrument into another language, often called the target language
Step 3	Reconciliation	Comparing and merging more than one forward translation into a single forward translation
Step 4	Back Translation	Translation of the new language version back into the original language
Step 5	Back Translation Review	Comparison of the back-translated versions of the instrument with the original to highlight and investigate discrepancies between the original and the reconciled translation, which is then revised in the process of resolving the issues
Step 6	Harmonization	Comparison of back translations of multiple language versions with each other and the original instrument to highlight discrepancies between the original and its derivative translations, as well as to achieve a consistent approach to translation problems
Step 7	Cognitive Debriefing	Testing the instrument on a small group of relevant patients or lay people in order to test alternative wording and to check understandability, interpretation, and cultural relevance of the translation
Step 8	Review of Cognitive Debriefing Results and Finalization	Comparison of the patients' or lay persons' interpretation of the translation with the original version to highlight and amend discrepancies
Step 9	Proofreading	Final review of the translation to highlight and correct any typographic, grammatical or other errors
Step 10	Final Report	Report written at the end of the process documenting the development of each translation

*These ten steps follow the ISPOR Principles of Good Practice: The Cross-Cultural Adaptation Process for Patient-Reported Outcomes Measures.

[1] Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. Value in Health, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x.

Appendix

Working Group Member Conflicts of Interests

At the beginning of the Working Group process, we ask all Working Group members to declare any conflicts of interests they have. We then circulate these within the Group to ensure transparency.

Name	Affiliation	Declarations	Track
Claudia Bandeira de Lima	Institute for Evidence-Based Healthcare at University of Lisbon School and Medicine Santa Maria University Hospital LógicaMentes –Center	None declared	B
Diane Li	Ai You Foundation	None declared	B
Javier Virues	Universidad Autónoma de Madrid	None declared	B
Merry Barua	Action for Autism	None declared	B
Neil Martin	Behavior Analyst Certification Board (BACB)	None declared	B
Svyatoslav Dovbnya	Naked Heart Foundation	None declared	B
Sudhanshu Grover	Action for Autism	None declared	B
Shaneel Mukerji	MHF Kolkata; India Autism Center	None declared	B
Sandra Willis	Columbia University	None declared	B
Tatyana Morozova	University of New Mexico	None declared	B
Weihe Huang	Ai You Foundation, Association for Behavior Analysis International	None declared	B
Amber Valentino	Trumpet Behavioral Health	None declared	A
Braden Josephson	Centria Healthcare	None declared	A
Dennis Dixon	Center for Autism and Related Disorders	None declared	A
Ellen Fittro	InBloom Autism Services	None declared	A
Hanna Rue	LEARN Behavioral	None declared	A
Johnathan Tarbox	University of Southern California; FirstSteps for Kids	None declared	A
Kim Strunk	Hopebridge	None declared	A
Kristine Rodriguez	Autism Learning Partners	None declared	A
Leslie Morrison	Easterseals Southern California	None declared	A
Peter Gerhardt	The EPIC Programs	None declared	A
Yagnesh Vadgama	Magellan Health	None declared	A

ICHOM Contact Information

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change

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