

UC Davis MIND Institute  
22q Healthy Minds Clinic  
Frequently Asked Questions

- 1) **What ages does the clinic serve?** We serve a broad age range of children and adolescents diagnosed with chromosome 22q11.2 deletion (Velocardiofacial, DiGeorge) syndrome and their families. The ages range from **infants to 18-years-old**. Specially trained physicians; a developmental behavioral pediatrician or a child/adolescent psychiatrist, provide examinations across this age span. Typically the developmental behavioral pediatrician examines children through 10 years. However, children 10 years or younger with a psychiatric history are examined by the child/adolescent psychiatrist. This specialist also examines all children 11- to 18-years-old for possible, emerging chronic mental illness and to assist with pharmacological management. A licensed clinical psychologist specializing in developmental neuropsychology examines children from infants through 14-year-olds. Psychologists who specialize in transition issues for those 15-years and older, such as identifying adolescents' vocational interests, examining for neurocognitive processes fundamental to becoming a safe driver, or interpreting personality development are not currently available in our clinic. Hence consultations with the child/adolescent psychiatrist can be enhanced if the family can arrange for independent clinical neuropsychological assessment and bring those results with them to the appointment.
- 2) **What information do I need to bring to the appointment(s)?** You should bring:
  - a) your medical insurance card,
  - b) the *completed* MIND Institute Clinics Patient Questionnaire,
  - c) *completed* parent and teacher screening questionnaires (e.g., BASC-2, SRS, NICHQ Vanderbilt),
  - d) if he/she has one, bring your child's *current* 504 plan, Individual Education Plan (IEP), Individual Family Service Plan (IFSP) or Individual Program Plan (IPP),
  - e) copies of previous evaluations such as completed by the school district psychologist, Speech/Language Pathologist, Occupational Therapist, private mental/behavioral health specialists, tutors, etc.
  - f) if you have them, bring copies of your child's most important medical records (e.g., psychiatric hospitalization intake and discharge reports, list of current medications, medical procedure reports, recent lab results, pediatric specialist reports, etc.).
- 3) **What materials, supplies or toys should I bring to the appointment(s)?** You should bring:
  - a) any assistive devices your child is prescribed/uses (e.g., glasses, hearing aides, FM system),
  - b) food items that may be unique to your child's diet (e.g., gluten free, high protein),
  - c) medications your child will need that day,
  - d) a fresh change of clothing and underwear if you worry that your child may have a toileting accident or upset stomach,
  - e) any toy or object that gives your child comfort but does not command their attention excessively (e.g., fluffy stuffed animal, security blanket versus hand-held video game),
  - f) special treats that might be used as an incentive.
- 4) **Should my child take their prescription medication on the day of the appointment(s)?** Yes, please assure that your child takes their usual medications at their usual times and dosages. Do not remove your child from any prescription medications on the day of the appointment unless specifically directed by the physician who prescribed them.
- 5) **How long do the appointment(s) take?** Appointments usually take most of the day with breaks to use the bathroom, for lunch, stretching, rest or playing. There will be short periods when your child or you may not be with a doctor (e.g., when the doctors consult with one another). Although you may bring activities from home that entertain your child (e.g., favorite movie DVD), the MIND Institute also has many child friendly activities available (e.g., Wii station, an enclosed, outdoor playground). We also sometimes have adult,

Child Life volunteers who can interact with your child, particularly if you and the doctor need to meet without your child present. However, these volunteers are not always available, so, if possible, it is a good idea to bring along a relative or friend who can watch your child while you meet alone with the doctor(s).

- 6) **Why does the bill for neuropsychological services charge more hours than the time our child actually spent with the psychologist?** We bill for all the time that is spent working on your behalf. This includes reviewing records and information from collateral resources, integrating the results of previous tests with our current test results, the in-person office visit(s), scoring/interpreting tests, preparing written reports, etc.
- 7) **Why does our insurance company only pre-authorize part of the neuropsychological services?** Many parents have specific questions about their child's ability to learn and would like our recommendations to facilitate his/her academic development. Although we try to accommodate this important need, many insurance companies consider this within the purview of the child's school district. Hence they will not pre-authorize the hours needed to examine and understand the child's academic development. Nevertheless, some families are able to have their child's school district complete a comprehensive academic evaluation prior to the appointment with our team. Typically the family needs to make this request in writing to their child's Student Study Team (SST). The school district will do this free-of-charge if they agree an assessment is necessary. This school-based assessment often involves the educator reviewing the child's academic history and performance, observing the child in the classroom and/or administering one of the common, individualized measures of academic development such as the Wechsler Individual Achievement Test, Third Edition (WIAT-III), the Process Assessment of the Learner, Second Edition (PAL-II), or the Woodcock Johnson Tests of Academic Achievement, Third Edition, Normative Update (WJ-III-Ach N/U). Please bring the report of the results of that assessment to the clinic appointment.
- 8) **The Student Study Team (SST) at our child's school has declined to examine him/her but we would like your recommendations to facilitate his/her academic development. What should we do?** If your insurance company will not pre-authorize that part of the examination, but you would like the service, you may pay for it out-of-pocket. Our medical office service coordinator will develop and discuss a fee-schedule with you. Alternatively, you can appeal, in writing, the SST's decision not to examine your child and enact your rights to due-process.
- 9) **My child attends private school or is home-schooled, how do I obtain an academic evaluation for him/her?** Apply in writing to the Student Study Team (SST) at the school your child would attend if he/she was in public education. The Principal at the public school can give you additional information. Your request for an evaluation must specifically state the concerns that your child has a disability that interferes with his/her ability to make appropriate academic progress.
- 10) **What will my child and I be doing during the appointment with the Developmental and Behavioral Pediatrician or Child and Adolescent Psychiatrist?** These specialists meet with parents and interview them about their child's history, health and concerns. They also examine the child or adolescent; sometimes with the parents present but sometimes they meet alone with the child or adolescent. They also review, score and interpret various questionnaires and screening tests as well as reviewing previous test reports and records. They consult with the clinical psychologist and other specialists as needed in order to optimize their care of your child. Sometimes they meet as a team with the family and clinical psychologist to discuss findings and treatment recommendations.
- 11) **What will my child and I be doing during the appointment with the Clinical Psychologist?** This specialist reviews medical, school and other records, administers, scores and interprets standardized questionnaires and also will interview the parent and child or adolescent briefly. However, she will spend most of her time administering, scoring and interpreting standardized tests of various mental functions as well as other behavioral and emotional factors. While your child responds to these tests, you also may be asked to complete several more specific questionnaires. Depending on room availability and other factors,

some parents are able to observe parts of the assessment from behind the one-way mirror. The psychologist also will consult with the Developmental Behavioral Pediatrician or Child and Adolescent Psychiatrist and interpret the integrated results and recommendations from the clinical appointments to the family. At that time we also will discuss recommendations for treatment or other interventions/supports.

- 12) Can I bring an electronic device (e.g., iPad, cell phone) to digitally record the doctors' interpretation of the test results and their recommendations?** Yes, as long as you do not distribute or post the recording without our permission, you may record the debriefing session with the 22q Healthy Minds doctors.
- 13) How soon after the appointment can I expect to receive the written reports?** Usually our doctors will have written reports prepared and sent to you within 2-4 weeks after the appointment.
- 14) What should I do to get my child ready for the appointment(s)?** You do not need to do anything special to prepare your child. However, it is ideal for your child to get a good night's sleep the evening before the appointment. Also encourage them to eat breakfast or bring snacks so they will not be hungry during the appointments. Some families like to make this a special day for their child so they leave siblings at home. Others like to bring siblings and have a family outing after the appointments. If siblings do come to the appointment, please bring a responsible adult who can supervise them while you are in your appointments.
- 15) What should I tell my child about the appointment(s)?** Most children worry that they may get a shot or have other painful or frightening procedures during the appointments. You can assure them that we do not plan any painful procedures. If a procedure is necessary (such as a blood draw if any medical concerns arise), we will do everything to help them feel comfortable. Most of the activities will be like things they do in school or day care. This includes talking to adults about their families and lives, things they enjoy doing, and what might worry them. It also includes doing things with their eyes and hands (e.g., looking at pictures, building and drawing), as well as using their minds and words to pay attention, listen, think and answer questions. Most children find the activities interesting and enjoy showing another adult their skills.
- 16) What about parking, meals and lodging?** Because the activities of the 22q Healthy Minds Clinic are not supported by research funds, meals, lodging, and in some instances parking, are at your own expense.
- a) **Parking:** We have 15 parking spaces facing our building that have been designated for patient/research parking. With your welcome packet, we will include a "voucher" to put on your dashboard for parking in these spaces ONLY. The vouchers are not to be used for the rest of the lot. If there are no designated patient parking spaces available, please purchase a \$6.00 day pass from the Kiosk and leave that receipt on your dashboard. At no time can a patient park in the "D" permit parking spaces, or any other parking space already designated.
  - b) **Meals:** We have a Café at the MIND Institute that offers cold breakfast foods (e.g., cereal, muffins, yogurt, juice) and lunch (e.g., salads, soup, sandwiches, soft drinks). It opens at 8:00 am and closes at 2:00 pm Monday- Friday. The Café also is closed when the server takes breaks from 9:15-9:30, 10:00-10:30 and 1:00-1:15 pm. Many choices for convenient fast-food or restaurant dining also are available within a short drive.
  - c) **Lodging:** Should you need to stay overnight, the Marriott, Courtyard Sacramento Midtown, 4422 Y Street, Sacramento, California, 95817 is within a short drive or walk to the MIND Institute. You can reserve a room by calling (800) 321-2211 or (916) 455-6800. In some cases families may prefer to stay at the Kiwanis Family House, 2875 50th Street, Sacramento, CA 95817 < [www.kiwanisfamilyhouse.org/](http://www.kiwanisfamilyhouse.org/) >. The Kiwanis Family House is next door to the MIND Institute. Their phone number is (916) 736-0116. If this is your preference, please let one of our coordinators know and they can send in a referral to schedule a reservation there.

**17) Do you need more information?** Please contact one of our coordinators by phoning (916) 703-0317 or emailing [elizabeth.boyd@ucdmc.ucdavis.edu](mailto:elizabeth.boyd@ucdmc.ucdavis.edu) .