

Conducting Family-Friendly Research

TIPS AND RESOURCES FOR RESEARCHERS



Communicating with families

- Use people-first language by referring to the person before referring to the disability or diagnosis; for example, “student with autism” instead of “autistic student.”
- Use family-supportive language to acknowledge the different forms that family constellations can take.
- Eliminate jargon by using familiar and understandable language; if you must use acronyms, be sure to explain what they mean.
- When communicating with people with limited English proficiency, ensure that anything you would ask or tell an English-speaking family also is communicated; an interpreter may be required to communicate effectively. Good communication with these families is important because language differences may accompany significant cultural differences.

Making participation accessible and convenient

- Make driving and parking directions available to families.
- Communicate transportation options, perhaps offering bus/cab fare so that costs do not exclude families of lower socioeconomic status.
- Offer flexible scheduling options to allow parents to work around their child’s nap and school schedules, or offer to come in the evenings or on weekends.

Compensating families for research participation

- Consider how compensation motivates families differentially (race or socioeconomic status)
- Communicate the compensation for research participation clearly. Tell families *who* will be compensated (the

child, the parent, or both?), *when* they will be compensated (immediately, or delayed?), and *how* they will be compensated (money, services, other?)

- Offer monetary compensation that is the most beneficial for participating families. For some, cash is preferable to receiving a check.
- Ensure that compensation is accessible and meaningful to participating families. For example, when using gift cards, make sure they are for stores that are geographically convenient and relevant for participating families.
- If services are offered as compensation, clearly communicate what families will receive (e.g., advice, a formal consultation), and for how long.

Following-up with families

- Obtain permission to follow-up with families; although many will be open to further contact, their research participation does not obligate them further.
- Ask families if they prefer to be contacted by phone, e-mail, or postal mail.
- Answer the family’s questions following research participation; rather than setting the agenda for follow-up meetings, researchers should let the needs of families dictate the content of these meetings.
- Connect families with resources and referrals for clinical assistance, support groups, and to other research projects.

Sharing the results

- Specify how a family will receive results before they participate in the research project. Communicate what they will receive (e.g. results of tests), and how they will receive this (in person or in writing).
- Explain that the research team is not qualified to give diagnoses, and encourage families to meet with their primary care physicians or school counselors, as appropriate, to determine next steps.
- Address privacy issues by asking for families’ consent before sharing any results; take care to disguise case studies to protect privacy.
- Disseminate study findings to the community through newsletters and other media outlets, so that anonymous participants may access results.

Please see reverse for resources.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See kc.vanderbilt.edu/studyfinder, (615) 936-0448. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has over 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)

TRIAD is a Vanderbilt Kennedy Center program dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training. See <http://TRIAD.vanderbilt.edu> or call (615) 936-0267.

VKC Reading Clinic

Provides intensive, evidence-based instruction and assessment for students in kindergarten through middle school. Contact readingclinic@vanderbilt.edu or (615) 936-5123.

Other Resources

- **The Arc US**
www.thearc.org, (301) 565-3842
- **The Arc Tennessee**
www.thearctn.org, (800) 835-7077, (615) 248-5878.
See also Tennessee chapters.
- **Regional Intervention Program**
www.ripnetwork.org, (615) 963-1177
- **Tennessee Developmental Disabilities Network**
www.tennddnetwork.org
- **Tennessee's Early Intervention System (TEIS)**
(800) 852-7157

Web Resources

- **4researchers** disseminates practical information for conducting research. www.4researchers.org
- **The Beach Center on Disability** offers supports on family-quality of life issues.
www.beachcenter.org/families/default.aspx
- **The Child Welfare Information Gateway** provides resources to support and preserve families through a respectful, strengths-based approach.
www.childwelfare.gov/famcentered
- **The Institute for Family-Centered Care** promotes the practice of patient- and family-centered care.
www.ipfcc.org/advance/researcher.html
- **Monroe Carell Jr. Children's Hospital at Vanderbilt** provides resources to equip families with information to use at home or during a child's hospital visit.
www.vanderbiltchildrens.com/interior.php?mid=39
- An article from the **National Association for the Education of Young Children** explores parental perspectives on early childhood education
www.naeyc.org/files/naeyc/file/ecprofessional/STSF_parentsandchildren.pdf

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