

### Children's Mealtime Recruitment

The Children's Mealtime Study seeks to learn about the interactions between parent feeding practices, children's mealtime behaviors, and what is being eaten by the child and parents. This project focuses on learning about children with intellectual disability/developmental disability (IDD). Participants engage in one 2 ½ to 3 hour visit, and keep a food record for three days at home. The study recruitment goal is one hundred and twenty participants 3-8 years old: sixty with IDD (with or without autism) and sixty typically developing (TD - receiving no special education services e.g. speech, OT, PT, or on an individualized special education plan).

All potential participants are initially screened on the phone. For the participants with IDD the study visit involves: 1) two psychological assessments: a structured interview with the parent using an assessment of various domains of development (Vineland) and a cognitive assessment of the child with a clinician (DAS); 2) the parent and child are weighed and measured; 3) the parent fills out nine questionnaires; 4) the parent is taught by a registered dietician how to keep a food record; 5) the parent keeps the food record for three days at home. The TD participants are involved in the same process but without the psychological assessments. All participants are compensated for the visit: \$45 for the parent; \$15 for the child; \$20 if the child doesn't qualify on the psychological assessments. When the food record is returned the participant receives another \$40. Compensation is given in the form of a choice of popular gift cards, and parking is free or reimbursed.

In addition to the inclusion/exclusion criteria, there were constraints on recruitment. Children's Mealtime Study collects self-report data from parents through questionnaires. We were careful not to recruit using language that might influence parent responses on the questionnaires e.g. if parents thought the study was about obesity they might misrepresent reporting sweets. We did not leverage the national media interest in childhood obesity prevention efforts or contact nutritionists, nutrition programs (e.g. WIC), professionals who work with families with feeding or eating issues to ensure that we did not bias our sample. We also did not give nutrition related workshops, or recruit at events that focused on nutrition which would have seemed like logical venues/sources.

In addition, we were constrained to English speaking/reading parents as all of the questionnaires are only validated in English.

The grant requested funding for a two year period. The timetable designated eighteen months for recruitment, and listed the following strategies: collaborations with local parent support networks, organizations, special needs listservs, newspaper advertisements, and online resources.

The Research Coordinator (RC) spent at least 16-24 hours a week on recruitment activities. Initial efforts involved contacting organizations which the Principal and Co-investigators knew about or had previous connections, and identifying new organizations through web searches and a combination of emails and phone calls. The RC also visited organizations and presented at small and large meetings; applied to public school research departments for approval to recruit; and networked at events where the project/Shriver Center set up an exhibit table.

The RC worked to create connections and relationships with key organizations by sharing information about the Shriver Center, and leveraging existing resources that could be shared, e.g. staff expertise. The intent was to express the wish to create connections that would provide give and take that would be mutually beneficial. The

hope is that these connections would exist over the life of the project and hopefully be maintained for future Shriver Research Projects.

By the end of eighteen months the RC had reached out to approximately 300 organizations including: early intervention, Headstart, private preschools, public school early learning centers and K-12, special education schools, special education collaboratives, Special Education Parent Advisory Councils (SEPACS); community organizations (e.g. Arcs, Family Support Centers, Autism Resource Centers, non-profit human services/disability organizations), parent support organizations, recreation and camps, advocacy organizations (e.g. Massachusetts Down Syndrome Congress, Federation for Children with Special Needs), Applied Behavior Analysis (ABA) providers, physicians, a speech pathologist, as well as the Department of Early Education and Care (EEC) and Department of Public Health.

Of the 300 organizations approached, 160 organizations supported the Children's Mealtime recruitment efforts. The outreach activities included: giving out brochures through Family Ties (a Federation for Children of Special Needs/MA Department of Public Health Collaboration which connects families of children with special needs); hardcopy mailings; posting to listservs and newsletters; attending parent nights or resource fairs; sending brochure/letter packets home to parents; making brochures/tear off flyers available on their premises. The RC or a Shriver staff attended approximately 10 events/conferences.

The Children's Mealtime Study also accessed the Intellectual & Developmental Disabilities Research Center (IDDRC) database of participants, and engaged students/parents in the Shriver LEND program. The study paid for advertising in the Metro and Brockton Parent's Magazine, as well as paid and unpaid mailings done by the Mass Down Syndrome Congress, Center for Children with Special Needs, and the Autism Resource Center at the Northeast Arc.

At eighteen months, the end of December 2014, the project had received 225 inquiries and had 22 participants with IDD and 29 participants who were TD--less than half the target. Throughout the eighteen months the project team met weekly, brainstorming about additional recruitment venues, strategies, and possible changes to recruitment and recruitment materials that might improve study enrollment rates. As a result, we submitted six IRB modifications. To ease the burden on participants we requested: 1) permission to do home visits; and 2) we requested that we be allowed to administer the Vineland (the parent interview that is used to determine eligibility) over the phone if the participant lived a long distance. To improve access to participants, we requested permission to do the following recruitment activities: 1) use the Shriver Center Intellectual & Developmental Disabilities Research Center (IDDRC) participant database; 2) ask participants to pass on information about the study to friends and family who might be eligible; 3) use social media; 4) increase the types of professionals engaged for recruitment support; 5) request permission to use a HIPAA waiver, so that we could ask physicians to mail information to patients about the study; and 6) request permission to run informational workshops for potential participants during which they would learn about a topic of interest, but would also meet study staff and learn about participation. We also requested permission to screen potential participants with the Vineland if the child had a syndrome often associated with IDD, regardless of whether they passed the phone screening; and to clarify the home visit option on recruitment materials.

The project received a no-cost extension through December 2015. In June of 2015 (with 30 IDD participants, and 33 TD participants) the Principal Investigator spoke with the funder and described the recruitment efforts to date. The funder was pleased with comprehensive nature of the efforts, and the program officer supported a second no cost extension which will end in June 2016.

Continuing recruitment included returning to core organizations and adding new ones. As time progressed, the conversations with these connections deepened, providing additional networking and resources. In part this was because the project began to offer workshops for families, and in part because the RC connected not only to direct care providers, but also to administrators who gave access and permission for agencies to engage with the study.

Some efforts were more systematic than in the previous year because of the reasons stated in the previous paragraph. The RC contacted the Statewide Director of Family Support at Department of Developmental Services (DDS) who provided access to regional meetings of contracted DDS agencies. For example, a connection made the previous year with the Regional Director at Early Education and Care (EEC) at the Massachusetts Department of Elementary and Secondary Education this second year provided the project with names and direct contact emails for CFCE (Coordinated Family and Community Engagement) grant coordinators. The CFCE grants provide for programs which run literacy activities, parent support groups, parent education, facilitate community planning between early care providers and community stakeholders, etc. These connections provided additional and more responsive access to public school preschool directors, special education directors, who could connect to parents.

It is difficult to track the success of individual recruitment efforts. Often potential participants don't remember where they heard about a study. The information in the chart below is a consolidation of efforts. More specifically, we had a good response, approximately 20/700 people, to a physician mailing using a HIPAA waiver. From these responses, we enrolled three participants. The Mass Down Syndrome Congress mailing had a response rate of 12/500 with an enrollment of six participants.

Recorded Inquiries by effort

Year	School Outreach		Community Organization		Listserv		Online Advertising		Events		Friend Referral		Mailing		Metro Newspaper		Miscellaneous	
	Inq	Part	Inq	Part	Inq	Part	Inq	Part	Inq	Part	Inq	Part	Inq	Part	Inq	Part	Inq	Part
6-12/2013	0		2		14	2	31	14	0		15	5	5	1	0		1	1
1-12/2014	33	6	41	11	2		23	9	0		8	2	16	8	9	2	6	1
1-10/2015	21	6	9	2	0		16	2	19	2	2	1	38	3	0		6	1

- Inq=Inquiry
- Part=completed participant
- There were an additional 47 inquiries with recruitment resource unreported

Reviewing recruitment over the past twenty eight months of the study the average number of inquiries per month has fluctuated (see figure below)

Recruitment rates by month

	Jan-13	Feb-13	Mar-13	Apr-13	May-13	Jun-13	Jul-13	Aug-13	Sep-13	Oct-13	Nov-13	Dec-13	Average ID recruited per month	Average inquiries per month	Annual inquiries per participant recruited (TD & ID)
TD participants	-	-	-	-	-		6	4	2	1	3	3			
ID participants	-	-	-	-	-	-	0	0	3	1	0	0	0.66		
Month Inquiries							12	23	11	6	10	10		12	72/23=3.13
	Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14			
TD participants	1	0	3	0		1	2	3	2	0	0	1			
ID participants	8	0	1	3	4	1	1	0	0	1	4	3	2.17		121/39=3.10
Month Inquiries	16	4	16	4	13	5	3	11	20	11	9	9		10.63	
	Jan-15	Feb-15	Mar-15	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15			
TD participants	1	1	0	0	1	0	2	0	0	1					
ID participants	1	0	3	1	2	2	1	2	0	2			1.4		101/20=5.5
Month Inquiries	3	1	4	15	9	21	14	3	12	19				10.1	

- 44 inquiries had no date and are therefore not recorded here.

It is not clear why the rate of IDD enrollments and inquiries fell in 2015. It may be that with a relatively small population the number of people being exposed to the study for the first time was saturated. The new recruitment strategies i.e. organizing workshops and presenting at higher level administrator meetings took RC time away from other efforts, and it may be that the additional relationship building has not (yet) yielded results. The project was disappointed with the research registries: DS-Connect and Williams Syndrome which did not yield any participants, and planned workshops did not attract sufficient participants. Recontacting organizations that helped in 2014 yielded fewer participants.

The study will be requesting a second no cost extension. We plan on recruiting from an out-of-state site that has 20-30 families that may qualify. To engage those families from a distance we may develop short video which we will disseminate through email or place on the study website. The study has not had the resources to engage in a social media campaign, but UMass Medical School Marketing Analytics has written an “article” about the study which they will disseminate through Facebook, LinkedIn, and Twitter.

We have tried to explain why recruitment has been so difficult and to garner lessons learned that might inform future project design. We heard from professionals that the monetary compensation was probably not sufficient to justify what families perceived as a major effort. We underestimated the number of competing demands on the families of young children with IDD, and the fact that the importance of participating in research is may not be understood by many families whose children have only recently been diagnosed. Young children do not receive a formal diagnosis of IDD until after the age of eight, which may also have affected parents’ response rate. Further, a number of professionals suggested that though our idea of offering workshops was constructive, many families aren’t able to find the time to participate in groups/workshops or programs. Suggestions might be to: 1) try to determine the size of the population of potential participants in MA, and determine if there are areas that are high density; 2) interview professionals or focus groups of potential participants before the study about compensation or design that would make participation feasible; 3) identify key partner organizations that could support recruitment and develop connections earlier in the process; 4) design the project so that the participant might receive individualized nutrition counseling as part of compensation; 5) design the project so as to minimize the length of the visit e.g. consider if any of the questionnaires could be done online; 6) begin the use of video and social media early in the study; and 7) make a more engaging study website.