



## Community Support Services, Inc.

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### STEP Study – Screening Tool of Feeding Problems

**CSS will begin participating in aiding our Volunteer Nutrition Instructor, Janice Goldschmidt, with her efforts to collect data relating to eating problems. Working with Janice, who is completing her Masters' in Nutrition at the University of Maryland, we will administer a short survey to specific CSS staff members asking questions regarding their client's eating patterns. This study is consistent with the health initiatives and nutritional goals maintained by CSS. We believe participating in this study would benefit your child and we would like to invite your son/daughter in this survey. Participation in this study will also produce data that will assist CSS in applying for future grants to help with cooking and nutrition areas.**

#### **Background:**

Janice Goldschmidt is a nutrition graduate student at the University of Maryland, College of Agriculture & Natural Resources, Department of Nutrition & Food Science. She has been collaborating with CSS since November 2013 and has led many popular nutrition, salad and cooking groups.

Eating difficulties displayed by persons with disabilities has been a growing area of research and interest among mental health professionals. Eating and meal-time behavior problems are extremely common among individuals with disabilities. Furthermore the consequences of untreated eating problems can be severe if not fatal. Despite these associated risks, little has been done to systematically identify these problems. The Screening Tool of Feeding Problems (STEP) was developed as a means to identify eating problems presented by persons with disabilities and thus facilitate the process of identifying those who would benefit from some type of behavioral or medical intervention.

The STEP has two forms consisting of the questionnaire itself as well as a score sheet. Contained in the questionnaire are spaces provided for the name of the client, the name of the informant, and the date of the evaluation. The STEP should identify in what area of eating related problems can the individual problems be classified (e.g. selectivity, skills, etc.)

This survey will not result in any formal diagnoses for your child, but the researcher will contact you to let you know if any areas of concern for your child were revealed. The names of the individuals being assessed in this survey will not be included in any publications or in papers presented at professional proceedings.

**If you are interested in participating in this study, please sign and return the attached disclosure form This disclosure grants CSS and Janice Goldschmidt the right to collect and use nutritional information to be used for the Screening Tool of Feeding Problems (STEP).**

We look forward to hearing from you and hope that you allow your child to be included in this research opportunity.

# University of Maryland College Park

<b>Project Title</b>	<b>Focusing on Food: Administering the Screening Tool of Feeding Problems (STEP) to Assess Individuals with Autism and Intellectual Disabilities at a Community-Based Center</b>
<b>Purpose of the Study</b>	<p>This research is being conducted by Janice Bailey-Goldschmidt at the University of Maryland, College Park, Department of Nutrition and Food Science. This project will attempt to identify and quantify eating disorders among adults (&gt; 18 years of age) at Community Support Services with autism and intellectual disabilities (ID). As part of this project, the researcher would like to assess your son/daughter/ward's eating patterns. We are requesting permission for your child to be included in this survey. In most cases individuals will be assessed by surveying an aide of long standing (six months or greater) through administration of a short survey. In a very few cases, it might be deemed more appropriate to survey the parent rather than an aide (if their current aide has not worked with them for a sufficient period of time).</p> <p>If you provide permission for your child to participate, please assume that an aide will complete the survey unless we contact you directly.</p>
<b>Procedures</b>	<p>The STEP survey assumes that the individual being assessed cannot provide appropriate or accurate status as to their eating patterns. Thus, STEP is intended to be administered to an aide who has been associated for at least six months with the individual being assessed. As explained above, it is presumed that parents would also be appropriate in certain circumstances to provide information regarding eating behaviors.</p> <p>Once your approval has been obtained, CSS staff will determine which aide is the most appropriate to complete the STEP survey. Please assume that an aide will complete the survey unless we contact you directly.</p> <p>The survey takes approximately four minutes to complete and requires that the aide/parent answer a series of questions about eating behaviors that they have observed in the individual being assessed. The questions are not highly technical and the individual administering the survey will answer any questions or clarify issues as the survey proceeds. Only one session is necessary per aide/parent and will be administered at CSS as part of the workday.</p> <p>Following completion of the survey, and in cooperation with CSS, all formal eating diagnoses for the individual in question will be noted directly from CSS files. Diagnoses will be considered formal only when accompanied by Diagnostic and Statistical Manual of Mental Disorders (DSM) coding.</p> <p>The 23 identified eating pathologies identified in STEP subsequently fall into these five relevant categories of eating pathologies:</p> <ol style="list-style-type: none"> <li>a. Aspiration risk</li> <li>b. Selectivity</li> </ol>

	<p>c. Feeding skill disturbances  d. Food refusal  e. Nutrition related</p> <p>Administration of STEP to an aide or parent will NOT result in a formal diagnosis of an eating disorder for your son/daughter/ward. Instead, it will only reveal possible areas of concern and issues that you as parent might want to pursue with a doctor. We will contact you with the results of the STEP survey and parents can make the decision as to whether formal follow up with a medical doctor is needed. At that time the researcher will answer any questions that you might have about STEP or research outcomes.</p>
<p><b>Potential Risks and Discomforts</b></p>	<p>Because your son/daughter/ward will not be directly participating, there are no risks to your child. You should be aware, however, that formal eating diagnoses will be noted from your child’s CSS file for comparison with survey outcomes. This will require access to your child’s Personal Health Information (PHI). All survey results and information collected from case files will be treated as confidential and kept in a locked cabinet.</p> <p>Should the research result in publication, no names of participants or individuals assessed will be made available. Your son/daughter/ward’s identity and information will be kept strictly confidential at all times.</p>
<p><b>Potential Benefits</b></p>	<p>There are no direct benefits to you or your son/daughter/ward, but some potential benefits include contributing to the existing knowledge base, and identification of eating pathologies for your child that might be treated therapeutically.</p> <p>While administration of STEP will not result in a formal diagnosis of an eating disorder for your son/daughter/ward, we will contact you with the results and parents can make the decision as to whether formal follow up with a medical doctor is needed. At that time the researcher will answer any questions that you might have about STEP or outcomes.</p>
<p><b>Confidentiality</b></p>	<p>Confidentiality will be maintained for your son/daughter/ward by removing all names from published materials. Only the researcher, advisor and Community Support Services (CSS) personnel will have access to the actual names of the survey subjects. All identifiable data (names, diagnoses) will remain in a locked cabinet in the researchers office and will be destroyed 5 years after completion of the data analysis.</p>
<p><b>Right to Withdraw and Questions</b></p>	<p>Participation in this research is voluntary and there is no coercion to participate.</p>

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	<p>Please know that if you decide to not have your son/daughter/ward participate, it will not affect their ability to participate in any other activities or access to services at CSS.</p> <p>If you as parent/guardian, later decide to withdraw from the survey, or if you have questions, concerns, or complaints, please contact the investigator:</p> <p style="text-align: center;"><b>Janice Bailey-Goldschmidt</b>  <b>301-801-2494</b>  <b>University of Maryland College Park</b>  <b>Nutrition and Food Science Department</b>  <b>0112 Skinner Hall</b>  <b>College Park, MD 20742</b>  <b>Janicebg9@msn.com</b></p>	
<b>Participant Rights</b>	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;"><b>University of Maryland College Park</b>  <b>Institutional Review Board Office</b>  <b>1204 Marie Mount Hall</b>  <b>College Park, Maryland, 20742</b>  <b>E-mail: <a href="mailto:irb@umd.edu">irb@umd.edu</a></b>  <b>Telephone: 301-405-0678</b></p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>	
<b>Statement of Consent</b>	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you and your son/daughter/ward voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
<b>Signature and Date</b>	<b>NAME OF YOUR SON/DAUGHTER/WARD</b> [Please Print]	
	<b>NAME OF PARENT/GUARDIAN</b> [Please Print]	

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	<b>SIGNATURE OF PARENT/GUARDIAN</b>	
	<b>DATE</b>	