

Neuromotor Clinic Evaluation

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Description

In February 2007, Children with Special Health Care Needs (CSHCN) Child Development Clinic Program staff developed a Neuromotor Clinic (NMC) to meet the needs of children with neuromotor delays. The following URLEND leadership project of Terry Holden, P.T, Alison Seppi, R.N, and parent, Diana Smith was implemented to evaluate this newly formed inter-disciplinary clinic by assessing family satisfaction by means of a survey. Sarah Winter, M.D. served as a mentor for this project.

Introduction

The NMC is a newly formed CSHCN clinic that began in February 2007. Sarah Winter, M.D. had previously been involved in a similar clinic, and was anxious to replicate one in Utah. We were interested in patient and family satisfaction of this new clinic and how to improve its value to families of children with special health care needs.

The NMC was developed to meet the specific evaluation needs of those children who have motor delays. This meets the criteria for the Maternal and Child Health (MCH) Pyramid by providing direct health care services for children with special health care needs. It supports MCH infrastructure building services by performing a needs assessment and program evaluation. The NMC is multi-disciplinary and holistic, in that families are directly involved in all aspects of their child's evaluation and treatment planning. One of the six performance outcomes described in the National Agenda for CSHCN is that families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.

The NMC is held twice monthly at the Salt Lake City CSHCN site. It is available to children and their families statewide but primarily serves children along the Wasatch Front. The core team includes a neurodevelopmental pediatrician, physical therapist, nurse, and family members. Other disciplines such as audiology, speech therapy, psychology, occupational therapy, orthopedics, neurology, genetics, and social work interface with the core disciplines of the NMC team. Referrals to and from these professionals are ongoing and crucial to meet all the special needs of a child served by the NMC.

The purpose of this project was to assess if this new clinic was meeting the needs of the families that it serves, by supporting families and providing evaluation and referral information they are seeking to ensure optimal outcomes for the child. Through the survey results, we have attempted to gain insight from the respondents regarding the effectiveness of the NMC clinical services. We will use this feedback to improve our clinic, with the goal of providing essential benefits to patient's families that will complement their medical home, while ensuring that their unique perspectives are understood. It will provide information for the CSHCN administrators and other CSHCN staff, to build upon and be accountable for program effectiveness.

Program Overview

A chart review was completed and defined characteristics of participants were documented. Forty-six charts (three charts were off site and unavailable) were reviewed of which 73% were male and 27% female. Patients were referred by a number of different sources, including 57% by the medical home, 12% by the Neonatal Follow-up Program, 9% by genetics, 9% by other health care professionals, 5% by early intervention programs, 5% by neurologists, and 3% by friends and school.

MCH authorizes appropriations to states to “Increase the number of low income children receiving health assessments, diagnosis and treatment of services.” Of the forty-nine families that were sent surveys, 43% had incomes less than 100% of the Federal Poverty Level (FPL), 26% had incomes between 100-133% of FPL, 6% had incomes between 185-225% of FPL, and 25% had incomes greater than 225% of FPL. Of interest, the Child Health Insurance Program (CHIP) and Utah Disability Medicaid (DM) eligibility is at 200 % of the FPL.

Concerns voiced by families during the intake process were varied and included global developmental delay, motor delay, speech delay, social and behavioral concerns, feeding problems, seizures, vision and hearing concerns, and specific concerns related to their child’s diagnosis, such as Muscular Dystrophy, Cerebral Palsy, Hypotonia, and Autism Spectrum Disorders.

The Peabody Developmental Motor Scales, second edition, was administered to patients to assess motor development. The average Gross Motor Developmental Quotient was 75 (5th percentile), Fine Motor was 75 (5th percentile), and the average Total Motor Quotient was 72 (3rd percentile). Six children were not tested but their scores would have been <1st percentile. The NMC made over 75 referrals to other programs or health care professionals as part of the treatment recommendations.

Procedures

A survey was implemented to elicit responses regarding 26 different aspects of the NMC. Carlos Munoz, a URLEND trainee, provided Spanish translation of the survey. In total, 49 surveys were sent to both Spanish and English-speaking families that had received services through the NMC between February and December 2007, excluding those that were deemed inappropriate referrals to the NMC. Twenty-six questions were posed, with two additional open-ended questions. These were included in the hope of gaining insight into areas where improvements could be made and to identify specific likes and dislikes of the NMC. Suggestions for improvement were requested and space was provided for parents and caregivers to indicate whether they would like to be contacted by a parent representative, Diana Smith, or by Walt Torres, social worker and Spanish interpreter for CSHCN. A total of forty-nine families were identified to complete the survey. Surveys were mailed directly to forty-four families and five families were randomly selected to be interviewed by phone. These families were notified by letter that they would be contacted for the phone survey. Ms. Smith attempted to call all five families several times, but was only able to speak with two families. We allowed three weeks time for the forty-four families to respond to the first mailing of the surveys. Then, we mailed another survey; return envelope and cover letter reminding them to complete the survey. In order to maintain confidentiality, only the secretary, who mailed out the numbered surveys, knew the names of the respondents. Surveys were mailed out with a cover letter explaining the

purposes for the survey and requested that the completed survey be returned in the self addressed stamped envelope. Families were informed that the results were confidential. Families were asked to rate their satisfaction regarding 26 aspects of their NMC experience. Respondents answered by means of a Likert Scale, with the options of *neutral*, *disagree*, *strongly disagree*, *agree* or *strongly agree* with the 26 questions. To analyze the data, a *neutral* answer was given the score zero; *agree* or *strongly agree* were given scores of one or two respectively; *disagree* or *strongly disagree* were given scores of minus one or minus two respectively. Data was entered into a Microsoft Excel spreadsheet. The mean score was calculated for each of the 26 survey questions. A URLEND didactic session on Program Evaluation was facilitated to obtain feedback from professional stakeholders in the community. These included administrators, parents, business partners, educators, and medical and health professionals. Other stakeholders include children with special health care needs, CSHCN providers, community referents, early intervention and school programs, Division of Child and Family Services, Primary Children's Medical Center programs and medical home providers. This feedback helped to guide us throughout the project.

Results and Discussion

We received nine returned surveys in the first mailing and ten in the second mailing. Total response was 21/49 or a return rate of 43%. The costs of this survey were minimal. Costs to perform this survey included postage (\$68.88), regular envelopes (\$4.12), business envelopes (\$1.60), printing of survey (\$12.60), and administrative support (\$80.30) for a total cost of \$167.50.

Overall, respondents gave favorable responses to the survey parameters. We grouped the questions into five broad categories. These included Intake Process, Clinic Environment, Communication, Clinic Experience and Billing and Referrals. Questions 1, 2, 3, and 8 pertained to the intake process. We attempted to determine the ease of the appointment scheduling process, and if the staff was helpful, polite and respectful. The mean scores were between 1.25 and 1.75 and indicated a fairly high level of satisfaction (Figure 1). *Politeness* and *respectfulness* of the staff received the highest scores and the question that *concerns were adequately addressed during the phone intake*, scored the lowest. Questions 4, 5, 6, and 7 were grouped to describe the clinic environment. Topics included *ease of locating parking* and *clinic cleanliness* and *comfort*. These mean scores also ranged from 1.25 to 1.75, with *the availability of interpreting services*, if needed, scoring the highest and *ease of finding clinic location* the lowest (Figure 2). Questions 15-18 and 21, 23 and 24 pertained to communication (Figure 3). We attempted to determine how well families' questions and concerns were addressed, whether reasons were understood for tests being ordered, and how responsive staff was to families' phone calls. Highest scores were for the *families feeling that they were involved in the decision-making process for their child's care*. This score is significant for the NMC team, since it is one of the highest goals for the clinic. Lowest scores were for the *perceived lack of information shared with the patient's medical home*. Although reports were mailed to every agency for which a release had been signed, it is possible that families were not aware that this had taken place. The clinic experience category included nine questions about the level of comfort experienced by the clients with the clinic format and flow. They included questions 9, 10, 12-14, 19, 22, 25, and 26 (Figure 4). These scores demonstrated the greatest variability, with the highest scores for *the team approach*

utilized in the NMC and the lowest for the family's [lack of] understanding of their child's disability after having met with clinic providers. This result is definitely an area that deserves closer scrutiny, since an increase in understanding by the child's family of their child's disability is an important value for the NMC team. Nevertheless, all mean scores for the clinic experience category were above +1 on the scale of -2 to +2. Lastly, questions 11 and 20 measured the helpfulness of referrals made by the NMC team and explanation of billing issues by support staff. Both *billing* and *referrals* were rated equally at +1, indicating satisfaction with these processes.

With such a small number of respondents, the validity of this data is unclear. However, we believe that it does provide us a peek into the families' impressions of the NMC and offers us insight and awareness of those areas in which we can be more sensitive and work harder to improve.

This survey, including families' hand scripted comments at the end, has been a useful and cost effective way to gauge recipient's satisfaction level with various aspects of the clinic experience, and, on this basis, implement beneficial modifications and to continue to enhance those areas in which client satisfaction is already high.

Recommendations from this Project

1. It may be helpful to offer a simple survey to other CSHCN clinics, so that areas of weakness and strength can be brought to the attention of clinic providers and administrators, in order to continually monitor and improve patient services. All providers strive to offer valuable, worthwhile clinic experiences for patients.
2. The NMC team should take steps to improve or increase the families' level of understanding of the child's disability, following their clinic experience.
3. The NMC team should provide better maps and/or directions to the clinic site.
4. Improve level of information regarding billing and financial matters.
5. Take measures to make parents aware that information is always sent to the medical home, with appropriate release.

References and Citations

Health Resources and Services Administration (1999). *National Agenda for Children with Special Health Care Needs: Measuring Success for Healthy People 2010 [A working document]*.

US Department of Health and Human Services - Health Resources and Services Administration - Maternal and Child Health Bureau, Division of Child, Adolescent and Family Health pp. 11-12, 27(G97MCO4453)

A Framework for Program Evaluation: A Gateway to Tools-Contributed by Bobby Milstein, Scott Wetterhall, and the CDC Evaluation Working Group Edited by Jenette Nagy and Stephen B. Fawcett http://ctb.ku.edu/tools/en/sub_section_1338.htm



Figure 1

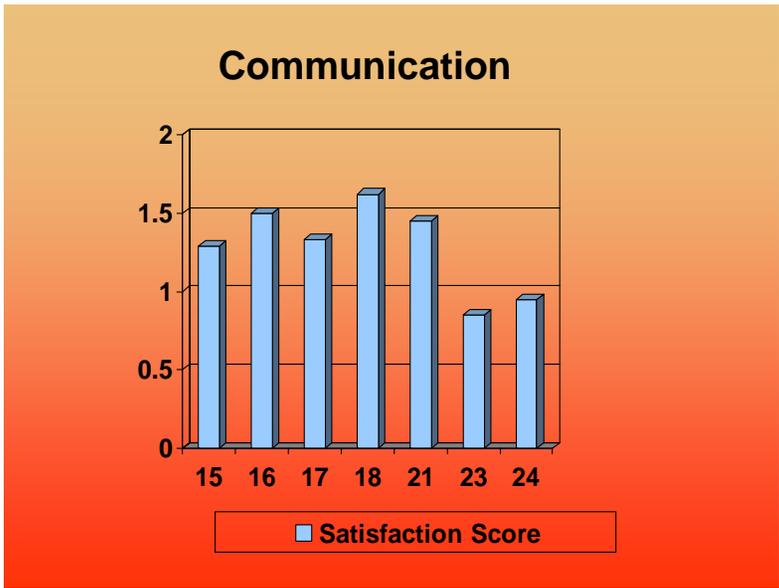


Figure 3

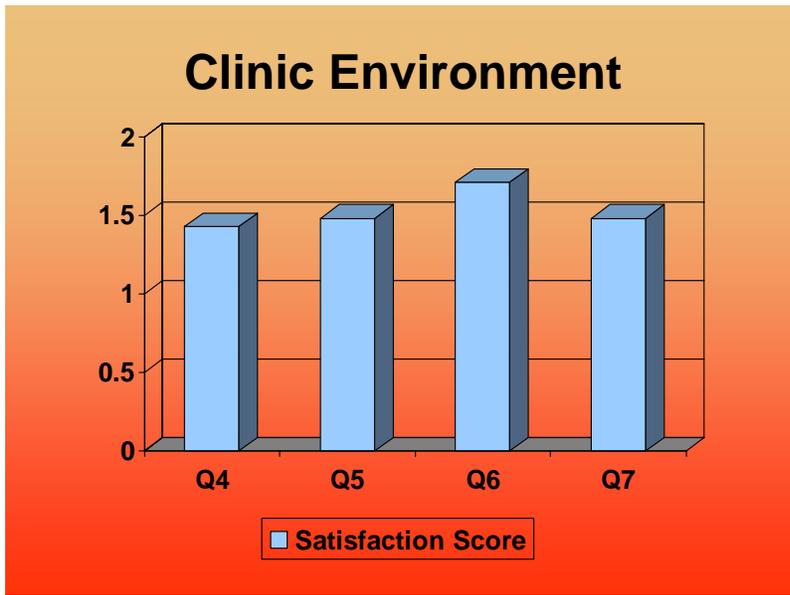


Figure 2



Figure 4