



Meeting Notes Spinal Cord Injury (SCI) Advisory Committee

MS Society, 900 S. Broadway Suite 200, Denver CO 80209

Friday, April 8, 2016
 10:00 am – 12:00 pm

Attendees

Andre Lang	Christiana Vonu	Lisa Dutkiewicz
April Kelly	Courtney	Samantha Saxe
Cara Lang	Dr. Jennifer Hartley*	Sonya Wytinck
Caroline Fleck	Jan Ruscio	Tsilat Petros
Chanda Hinton	Jill Karno	

*Indicates Call-in Participation

I. Welcome & Introductions

II. Approval of March Notes

- a. Meeting notes from March’s meeting were approved by the group.

III. Updates & Follow-up

- a. Waiver was approved by CMS.
- b. There is a new amendment on the waiver to comply with FLSA. CDASS is removing agency with choice model. It is open for public comment through 4/30/16.
- c. Sam and Chanda had an initial meeting the data subcommittee.
- d. Sam only received feedback from half the group on the materials that were sent out to the group. Please send your feedback to Sam.
- e. Chanda Plan has been enrolled as a provider and will start providing services on May 16, 2016.
- f. Jan has started the provider application process.
- g. Integrative Health application is pending approval.
- h. The PEAK Center at Craig Hospital is interested in becoming a satellite location for The Chanda Plan Foundation. The foundation is currently writing a proposal to figure out how that would work.
- i. If there are other providers that are interested in having a satellite location(s), please talk to Sam. Keep in mind that all locations have to be listed under rendering



server locations on the provider enrollment application. Also the facility needs to be certified by the Department of Public Health and Environment.

- j. Lisa D. introduced Caroline to the group and thanked her for considering the Medical Provider position.

IV. Study Design with NRC

- a. National Research Center is a small independent private firm that does social science research work with public agencies.
- b. Sonya Wytinck is the primary investigator for the SCI waiver independent evaluation with NRC. She was in charge of the first three years of the evaluation.
- c. The study did not have enough data points and consistent client participation the first time around. The goal today is to talk about pain points from the previous study and provide tangible recommendation to NRC to incorporate into the study.
- d. The evaluation is comprehensive. It includes quality of life, measured health outcomes, and financial claims data. However today we want to focus recommendations on the quality of life survey and self-reported health outcomes evaluation forms.
- e. Objectives
 - i. Collect strong data
 - ii. Increase participation
 - iii. Mitigate Pain Points
- f. Things to Consider
 - i. Frequency
 - ii. Format of Forms
 - iii. Administration of Forms
 - iv. Response Time
 - v. Additional Metrics
- g. Brainstorm Session – What could we do more off, less of, better or different?

More	Less	Better	Different
1. Emphasis of importance of study and participation 2. CM (Quarterly) contacts to remind clients of purpose/statement/script 3. Reminder of mission/pilot program 4. Add mission to evaluation form	1. Frequency of evaluation 2. Quarterly too difficult to track 3. Same schedule for all waiver participants	1. All initial forms completed before initial appointment 2. Onsite completion of forms at providers office after appointment with the help of administrative staff 3. Provider/Client/CM education on importance 4. Accountability on all levels. 5. Consistent guidance and training	1. Requirement of Participation to receive services (all therapies) – CDASS Model? 2. Adding one page survey to each visit – 3 questions at each visit? 3. Provider evaluation forms



Format of Forms	Frequency
<ol style="list-style-type: none"> 1. Form 2 & 3 – every six months 2. Keep forms 3 & 4 as is (UN forms). 3. Add Annual Satisfaction survey 4. Add qualitative/commentary questions – TBD (i.e. “What changes have you noticed?” 5. Form 2 – Add mood/mental health/spirit related questions 6. Pain scale – differentiate between general pain, muscle pain and nerve pain 7. Should add sleep related questions 8. Should add client’s goals – pain relief or mobility? 9. Provider Administered 10. Web-based? 11. NRC to send/collect eval forms for home-based clients 12. Agency-based: Admin assists w/ forms 13. Providers collect 1-pager at each visit and submit 	<ol style="list-style-type: none"> 1. Annual Satisfaction Survey (Client, CM, & Provider) – start next year 2. Full set of forms – every six months 3. 1 pager “soap notes” each visit (committee to recommend questions – consider provider comments) – Send to NRC every six months 4. Set schedule for all individuals 5. Due in April and October 6. If initial is less that one month prior too due date, wait till next survey date. 7. Respond to NRC by 1st week of May and Nov.

h. Additional Notes from Brainstorm Session

- i. New provider model could affect evaluation process.
- ii. Self-reported evaluation takes about 15 minute to complete.
- iii. Providers should schedule extra time when evaluation are due and ask clients to come in early or stay late to complete the form.
- iv. Outline a consistent detailed process on how forms are administered and collected.
- v. Change language to place emphasis on participation in the study since regulations does not make participation a requirement.
- vi. Participation in the study needs to be emphasized for the client, provider and case managers.
- vii. Talk to the Department about possible ways to make participation in the study a requirement (possibly copy the CDASS model or find out if providers could require participation?).
- viii. Create a document with the roles and responsibilities of participants, case managers, and providers.
- ix. Educate and encourage participants about the study.
- x. Keep all wavier clients on the same schedule to fill out evaluations.



- xi. Include explanation of schedule on welcome packet.
- xii. Evaluations should be done twice a year on set schedule (Suggested dates April and October).
- xiii. Evaluation should be mailed to NRC on the first week of May and November.
- xiv. If clients join the waiver the month before evaluation are due, providers should skip the upcoming evaluation.
- xv. Figure out how to handle clients that miss their evaluation appointment?
- xvi. Include one page “soap note” survey at every visit with a few quick questions.
- xvii. Include qualitative/ open ended questions to be more person centered.
- xviii. Change the word “depression” to mental health or mood.
- xix. Committee should focus on coming up with 3-5 questions for the one page survey at the next meeting (Close ended questions will be easier to include in the study).
- xx. One pager survey should be collected by the providers and send to NRC every six months.
- xxi. Consider including provider’s observation (each rendering provider) in the study (i.e. Do you notice improvement in client?).
- xxii. Provider’s observation (qualitative survey) should be a separate page from the one pager survey and should be part of the six month study.
- xxiii. Should add over all waiver/study experience survey – annual satisfaction survey (similar to the one that was done at the end of the first three years). It was a web based survey that was followed up with phone call from the Department.
- xxiv. Annual satisfaction survey should not be on the same schedule as the six month evaluation and should come from NRC. Should also include client, case management and provider satisfaction.
- xxv. If client is being seen by individual providers, NRC will be responsible for the evaluations. If client is being seen by a center, the center will be responsible for the evaluations. Sam and case managers will keep track of individual providers and center based clients.
- xxvi. Evaluation could be web based. It will eliminate data entry and mailing forms to NRC.
- xxvii. Forms:
 - 1. Form I – One page health history and background questions. Only done at initial appointment.
 - 2. Form II – Health Assessment questions (smiley face page). Used to be



done every 3 months. Now it will be done every six months.

3. Form III – Quality of Life Assessment (UN form) will be done every six months.
 4. Form IV – Functional Assessment – Takes longer to fill out and includes question to things that do not change that much - Annually.
 5. Form V – Service/Care Plan
 6. Annual satisfaction survey will be added next year.
- xxviii. Sonya recommends not to make changes to forms 3 and 4 as they are from World Health Organization form.
- xxix. **Action Item:** Dr. Hartley will send sample questions to same for the one page survey.
- xxx. **Action Item:** Think about what metrics to include to forms.
- xxxi. **Action Item:** Brainstorm ideas/questions for the one pager survey.
- xxxii. **Action Item:** Sam will send qualitative survey from last study.

V. **Public Comment (external stakeholders only)**

- a. No public comments were made

VI. **Next Meeting**

- a. Friday, May 6, 2016 10:00 am – 12:00 pm
- b. MS Society, 900 S. Broadway, Denver, CO 80249

VII. **Adjourn**

