

## Inaugural NDC Meeting notes Wednesday, September 24, 2014

For those unable to attend the Inaugural National Disability Coalition (NDC) meeting on Wednesday, September 24, 2014, in Washington, DC, please do the following to listen to the full audio recording of the event:

Dial toll free: 1-888-203-1112

Enter passcode: 6537220#

Once listening to the meeting:

Press 5 to return to the beginning

Press 7 to progress 30 seconds

Press 8 to pause

### **Topic One: How can we use the knowledge base of our stakeholders in supporting the disability decision process?**

#### **Presenter: Ethel Zelenske**

- Recommends changing NDC name to ND Outreach
- Not happy with IdeaScale as a platform for comments—it is confusing, unable to send attachments in IdeaScale and prefers email alerts with instructions, hard to identify commenters, hard to identify which question to answer and how to get to the next questions after answering the last one.
- Concerns regarding frequent unilateral changes at SSA
- Recommends getting outside the DC Beltway to obtain comments—regional listening sessions are helpful
- Brown bag lunches have been successful in DC
- Use target outreach, quarterly
- Reviewed NPRM and Advanced NPRM as appropriate ways to obtain comments
- Likes outreach hearings with experts and consumers prior to NPRM process

#### **Responders:**

- Huntington's Disease Society of America: Need to recognize cognitive deficits in Huntington's disease and use the organization to connect to specialist when writing policy. "Just ask them."
- AARP: Direct mail, social media, live chat, IdeaScale does not work for them due to scrolling and the platform was "clunky"
- International Vocational Experts: bulletin boards to include attachments, google docs, survey monkey, Twitter and Facebook and use direct board on website that allows external individuals to post.
- Wright State University: use newsletter to connect on legislative issues

**Topic Two: What factor and methods would you suggest we consider as evidence of an adult's ability to function in work settings?**

**Presenter: Lisa Ekman**

- Use individualized assessment for functioning as disability is diverse
- The grid should be retained as is
- If using a new tool, do not give great weight that overlooks the direct medical providers who are licensed to give that type of special care
- Be aware that a computer assessment is just a snapshot
- Be aware of limited English proficient claimants in computer assessments
- Most increases in life expectancy are for people who are of a higher economic level.

**Responders:**

Full Circle Employment Solutions (Amy Vercillo)

- Concerns with step five of sequential evaluation in the light and light to sedentary areas.
- Look at 50-54 age range especially for consideration to improve the grid
- Need more flexibility in the grid at the 50-54 age range especially

Wright State University (Joseph Keller):

- Use rehabilitation counselor in the assessment who are specially trained in this area

NIH:

- Look at daily functions on a daily basis

Steven Ostrega:

- The theory that one size fits all in assessing functioning is not a good model. Assessment in the private insurance industry includes ergonomics, workday scheduling alternatives, and alternate work locations like work at home per individual. Work with the disabled person early in the disability process.

Lisa Ekman:

- Pointed out two major differences in SSA that is unlike the private insurance industry. First, the claimant has no recent job experience in SSA most of the time. Second, SSA has step five of sequential evaluation that has to look at other work, not returning to past work.

---

**Topic Three: How can we enhance the medical evidence available for disability decisions?**

**Presenter: Steven Ostrega**

- Insurance provides income replacement.
- There are three concerns by insurance in obtaining evidence: The first is making the right decision. The second is making a timely decision. They have 45 to 105 days to make a decision. Thirdly, have technical/mechanical protocol in place to process efficiently. Moreover, a big difference is how media is viewed.
- He noted diagnosis does not equal disability and that most people want to return to work. They get depressed if not getting a decision timely and then their mind set turns to not being able to work.
- Therefore, another factor is to find out if there is a potential to return to work. He agreed the biggest problem is getting the right evidence timely.
- His company focusses on a remodel of the intake process. Reduce claim takers caseload by using an automated telephone process, increase vocational rehab experts and medical specialties. Use peer reviews when it looks like there is a denial. Use consultations for these cases. Utilize a verbal authorization.

**Responders:**

Huntington's Disease Society of America:

- People with many disabilities may take too long to use the automated telephone options.

Linda Landry, Disability Law Center:

- Claimants need assistance that electronics cannot provide. Often terms used in disability are not clear. Even the homeless need more assistance that is not often given.

Vanessa Mae, Disability Resource Consulting Service:

- Wants us to use Vocational Experts more and to use the CIGNA model.

Winthrop Cashdollar:

- To obtain unproductive sources, use peer-to-peer telephone calls.

NOSSCR:

- Suggests SSA expand medical sources to include Physician Assistants.

National Association of Disability Representatives:

- Suggests we use more representatives to obtain evidence.

Wright State University:

- Use hierarchy of credentials to reasonably evaluate and refer for further questions.

Jeanne Morin: National Association of Disability Representatives

- SSA must be more directive and specific in what they ask providers