### **April-May 2004 NACC Clearinghouse on ICF Messages**

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### 1. TENTH NACC CONFERENCE ON ICF JUNE 1-4 IN HALIFAX

Plans for the Tenth Annual NACC Conference on ICF to be held June 1-4 in Halifax are finalized. On June 1, we will have a 10am to 4pm "Tutorial on ICF". Trainers include Nenad Kostansjek of WHO, Alex Ruggieri of Mayo Clinics, Marijke de Kleijn of the Dutch ICF Collaborating Center, and Geoff Reed of the American Psychological Association. Fifty persons are registered. About 89 persons from 11 countries have registered for the June 2-4 ICF meeting. We will have Plenary and Concurrent sessions with 36 papers to be presented in the following sessions: International Updates, WHO Update, The ICF Clinical Procedural Manual, Assistive Technology and ICF, ICF Based Assessment Tools, Clinical Application of ICF by Professional Associations, Crosswalks of ICF to Other Assessment Tools, The Corpus of ICF Concepts, The Application of ICF

to Specific Populations, and Canadian Work in ICF. About 10 poster sessions are also expected. The entire focus and official theme of the meeting will be on "Advancing the Research Agenda in ICF". There will be a reactor panel to comment on the research agenda comprised of Dr. Ed Sondik, Director of NCHS/CDC, Dr. Kate Seelman, former Director of the National Institute on Disability Rehabilitation and Research, and several prominent Canadian health officials. More information can be found on the <a href="https://www.icf.conference.com">www.icf.conference.com</a> website. The best 16-18 papers of the meeting will be published in the book *Disability and Health: Advancing the Research Agenda for ICF*. It will be Volume 3 in the series by Nova Science Publishers, and is scheduled for publication early in 2005.

### 2. ICF-CY SOON TO BE ON WHO WEBSITE

Keep checking <a href="http://www.who.int/classification/icf">http://www.who.int/classification/icf</a> -- soon the ICF adapted for Children and Youth (ICF-CY) will be there in draft form as it is being field tested. The ICF-CY extends the coverage of the main ICF volume through the provision of expanded content and increased detail to cover body functions and structures, activities, participation and environments unique to the growth and development of infants, toddlers, children and adolescents. The draft version of the ICF-CY and related assessment materials will be posted on the WHO website for field trials. Evaluation focuses on review of content by individuals knowledgeable about the development and functioning of children and youth. Parents, professionals and other stakeholders complete a survey on the coverage and applicability of the ICF-CY for administrative, clinical and research settings. The clinical applicability of the ICF-CY will also be examined using four age-group questionnaires; infancy (0-2), early childhood (3-6), middle childhood (7-12) and adolescence (13-18). The field trial involves coding of limitations of function, activities, participation and environmental factors in children and youth with chronic conditions and disabilities as well as inter-rater reliability analyses. There is wide spread national and international interest in the ICF-CY and evaluations will be carried out in clinics, schools and other settings providing services for children in all WHO regional sectors. Findings will inform the preparation of the final draft and define the sensitivity and comprehensiveness of the ICF-CY for use in administrative, clinical and research settings to document functional limitations of children of different ages and health conditions. For more information, contact: Rune J. Simeonsson, Ph.D., M.S.P.H., Frank Porter Graham Child Development Center, CB #8185, UNC, Chapel Hill, NC 27599-8185, tel (919) 966-6634, FAX (919) 966-0862, Rune Simeonsson, [simeonsr@mail.fpg.unc.edu].

### 3. GRAY WINS \$250,000 ICF GRANT FROM NCMRR/NIH

Dr. David Gray of Washington University recently won a \$250,000/3year "R-21" grant from the National Center for Medical Rehabilitation and Research/National Institutes of Health. The grant title is "Rehabilitation Outcomes, Community Participation and ICF". The purpose of the proposed research is to further develop a new set of measures of participation and environmental factors related to participation by linking them to functional capacity, reducing survey completion time using computer assisted web based testing, and creating a data feedback and computational system that provides both

individual and aggregated data. This project will improve the psychometric properties of three existing assessment instruments (CORE, PARTS/M and FABS/M) by using cognitive testing among an expanded sample population to further refine and test these instruments. After the cognitive testing of new items, the surveys will be put into a computer assisted form and alpha tested by people with mobility limitations who have experience in computer-assisted testing. After revising the computer-assisted form of the survey, a web based survey will be created. The web based survey will be made available to 1,200 individuals who meet the inclusion criteria of having mobility impairments that limit their ability to walk three city blocks or who use mobility devices for moving in their environments. The results of these surveys will be used to establish standards scores for different core set of people with mobility limitations. These standard scores will then be used to establish outcome markers for rehabilitation into full participation in the community. The research data combined with input from experts will be used to develop a user-friendly data display for individual and aggregated data that allows users to examine where they fit with regards to participation in their communities. Finally, a profile will be created for users that will automatically match their participation characteristics and environmental barriers and facilitators to potential resources that could enable them to increase their participation in their communities. Incidentally, David now uses the new \$35,000 iBOT wheelchair, which goes backwards up steps, stands up tall, and more. That's the St. Louis arch in one of the photos. For more information, contact:

David B. Gray, Ph.D.

Associate Professor of Neurology and Associate Professor of Occupational Therapy Program in Occupational Therapy Washington University School of Medicine Campus Box 8505 4444 Forest Park St. Louis, MO 63108 314 286-1658 FAX 314 286-1601 grayda@wustl.edu

#### 4. VELOZO WINS \$250,000/3 YEAR NCMRR/NIH GRANT

Dr. Craig Velozo of the University of Florida recently won a \$250,00/3year "R-21" grant from the National Center for Medical Rehabilitation and Research/National Institutes of Health. The grant is to "Develop a Computer Adaptive TBI Cognitive Measure Based on the ICF". Cognitive functional status measures are critical tools for research on the effectiveness of rehabilitation interventions for traumatic brain injury (TBI). Global functional measures, such as the Functional Independence Measure (FIM), are widely used in rehabilitation settings, but only provide a cursory evaluation of cognition. Traditional neuropsychological measures, while standardized and psychometrically sound, are lengthy and often criticized for having weak ecological validity. The purpose of this project is to use the International Classification of Functioning Disability and Health (ICF) as the foundation to build an ecologically valid item bank and computer

adaptive testing (CAT) prototype for an applied cognitive measure for TBI. Modern test theory provides a basis for developing a measure that is both efficient to administer and precise for assessing cognition along the continuum of TBI recovery. Item Response Theory methodologies, specifically Rasch analysis, can be used to calibrate items thereby providing a means to match item difficulties to cognitive ability levels across stages of TBI recovery. CAT technology provides a mechanism to administer a small number of items to an individual, based on his/her cognitive ability level. The purpose of this paper is to present the design for a funded planning grant. Literature reviews of existing instruments and theoretical models will guide creation of a large item bank (300-500 items) reflecting cognitive behaviors commonly observed throughout TBI recovery. Next, health care professionals, patients and caregivers will be interviewed to expand and fine-tune the item bank. Upon completion of the modification of the initial item bank, a paper and pencil version of the instrument will be pilot tested on 50 patients in acute hospitalization, inpatient/outpatient rehabilitation and 6-months post rehabilitation. Selfreport, therapist and caregiver administrations of the instrument will be compared to a "gold standard" abbreviated neuropsychological assessment to identify the most appropriate rater at each stage of recovery. Finally, a web-based CAT prototype of the instrument will be developed and administration feasibility will be determined by feedback following healthcare professional, patient and caregiver administration. This planning grant will result in the item and CAT development necessary for reliability, validity and sensitivity testing of the TBI cognitive measure in a multicenter trial. The long-term objective is to develop an efficient, precise and ecologically valid instrument to evaluate outcomes of TBI interventions. For more information:

Craig A. Velozo, Ph.D., OTR

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UF OT Dept. Web Site: <a href="http://www.hp.ufl.edu/ot/">http://www.hp.ufl.edu/ot/</a>

Ph.D. Rehab. Science Web Site: <a href="http://www.hp.ufl.edu/rehabsci">http://www.hp.ufl.edu/rehabsci</a> ICF Computerized Adaptive Measure: <a href="http://www.ICFmeasure.com">http://www.ICFmeasure.com</a>

### 5. \$10 MILLION IN CROSSCUTTING RESEARCH MONEY AVAILABLE FROM CDC

While the letter of intent is due May 24, the application deadline is June 22, 2004. The CDC intends to commit up to \$10,000,000 in FY 2004 funds for approximately 20 new grants in response to this RFA. The award provides up to three consecutive 12-month budget periods within a project period of up to 3 years. An applicant may request a budget for direct costs of up to \$300,000 per year. Applicants should focus their investigations, which will ultimately make a substantive contribution to CDC's overarching goals and have a significant impact on people's health status. Specifically, the research outcomes should ultimately translate into extended lifespan or improved quality of health at any or all of the life-stages, and/or should substantively contribute to

people's protection from non-occupational infectious, environmental, or terrorist threats. http://grants1.nih.gov/grants/guide/rfa-files/RFA-CD-04-001.html

#### 6. NEW FREEDOM INITIATIVE ICF SUBCOMMITTEE MEETS AGAIN

The New Freedom Initiative Workgroup ICF Subcommittee is sponsored by the Office on Disability/HHS. On April 22, Paul Placek and Marjorie Greenberg participated in the second meeting of the Subcommittee. It was held in the Humphrey Building in Washington, D.C. and was chaired by Margaret Giannini, M.D., F.A.A.P., Director, Office on Disability. Participating in person and on the phone were Saadia Greenberg of AoA, John Crews of NCBDDD/CDC, Margaret Schaeffer of ACF, Paul Placek (as Facilitator), Tamara Clay of IHS, Carolyn Rimes of CMS, and David Gray of Washington University (Co-Facilitator). There were three presentations/discussions. First, John Crews discussed his new position as the lead scientist with the Disability and Health Team in the National Center on Birth Defects and Developmental Disabilities/CDC. John has used the ICF (and its predecessor, the ICIDH) extensively in his research on vision impairments and related secondary conditions and he has 17 ICIDH/ICF publications to his credit. To quote John: "ICF is the currency for our research...ICF is a Swiss army knife...ICF is the conceptual framework applied to my analyses of how vision impairment relates to activities and participation..." The second presenter was Carolyn Rimes of the Center for Medicare and Medicaid Services. She described a set of six articles in Health Care Financing Review (Vol. 24, No. 3, Spring 2003) which addressed functional status and the ICF. Marjorie Greenberg was the third presenter and discussed a draft of the "Roadmap for the Implementation of ICF" which is being developed for the October 2004 WHO FIC Network Meeting in Iceland. The document includes a "SWOT Analysis of ICF" (SWOT =Strengths, Weaknesses, Opportunities, and Threats) which lists about 50 ICF strengths and weaknesses. This Roadmap grew out of the St. Louis NACC meeting in 2003, and is being considered by the WHO FIC Implementation Committee chaired by Peter Goldblatt and Marijke de Kleijn. The third meeting of the New Freedom Initiative Workgroup ICF Subcommittee is scheduled for May 27 at the new headquarters of AHRQ. Janet Valluzzi is hosting, and AHRQ Director Carolyn Clancy will join the group.

## 7. DISABILITY ITALIAN NETWORK HAS FIRST ICF NATIONAL TRAINING MAY 2004

During the week of May 24, the Disability Italian Network (DIN) is having its first national training course in Rome. The ICF course, developed by DIN in collaboration with WHO, is divided in two courses: ICF Basic and ICF Advanced Course.

- 1. Basic Course (80 Registrants): it is an eight hour course on: brief history of disability and of classifications, ICF basic principles, ICF structures and background, differences between classifying, measuring, assessing, impact on national legislation and application in different settings, presentation of ICF tool box, core sets and WHO DAS. Also covered: the ICF "revolution" in health and disability sector; the ICF in Italy project; ICF in the world; perspectives; projects and contacts.
- 2. Advanced Course (40 Registrants): 3 days courses + 3 months distance learning (DL)
- + 1 day evaluation and exam. This three-day course is structured as follows:

Day 1. ICF structure, chapters, domains etc., how to code, how to use the different qualifiers, when to use them, difficulties and faq.

Day 2. ICF checklist,: how to use it, coding case vignettes. Use of checklist in different settings (rehabilitation, administration, statistics etc.)

Day 3 WHO DAS: description and use of WHO DAS, how to assess, video cases of interviews with actors, coding, exercises of coding case vignettes, of backcoding and from codes rewrite case histories.

Three months with distance learning methodology. DIN tutors will have a faq site, a question and answer with pupils about the homework. Each pupil will have to code ten pre-assigned cases, prepared and tested by DIN, and will have to write 3 cases with coding. Each pupil will have to do 5 complete coding with ICF checklists as well as assessment with WHO DAS 2 in real cases which each participant sees in his/her work.

Final day: each tutor is doing an evaluation of homework done by pupils 15 days before final evaluation. The last day is also to have forum discussion of the application of ICF in each participant's setting, difficulties, group discussion etc. Exam on the whole course. All cases are collected by DIN's databank.

All training participants are members of the net that is growing in Italy and that is coordinated by DIN; DIN reports to WHO. WHO Collaborating Centres will be updated on how the first course was received. Jerome Bickenbach, DIN's consultant for the preparation of the training for trainer part, and designee of WHO to collaborate with DIN, will join us in Italy to assist. In the next months the course, prepared by DIN and also given to the Italian Ministry of Welfare for the "ICF in Italy Project: pilot project ICF and labour sector" will be available in two languages for distance learning. For ICF in Italy project: see <a href="www.welfare.gov.it/icf">www.welfare.gov.it/icf</a>. For more information about the training, contact: Dr. Matilde Leonardi, Neurologist, Paediatrician

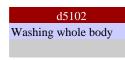
Coordinator

International Scientific Research and Disability Project Scientific Coordinator and WHO Liaison ICF In Italy Project Scientific Direction Italian National Neurological Institute C. Besta Via Celoria 11 20133 Milan Italy

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E-mail: leonardi@istituto-besta.it

## 8. ILLUSTRATED VERSION OF ICF AT <a href="http://www.tokyo.image-lab.or.jp/icf/ill/english">http://www.tokyo.image-lab.or.jp/icf/ill/english</a>



Applying water, soap and other substances to

the whole body in order to clean oneself, such as taking a bath or shower.

Tai Takahashi and Jiro Okochi of Japan have developed the illustrated version of ICF in English and Japanese. The website address of the English version is <a href="http://www.tokyo.image-lab.or.jp/icf/ill/english">http://www.tokyo.image-lab.or.jp/icf/ill/english</a>. This very practical tool will facilitate the understanding of ICF by adding illustrations to each ICF code. The authors also designed the website to allow other languages to be added simply to the library. The Japanese and English language versions of the web site are free to use, and the web pages enable the user to view the classification via a hierarchical structure with accompanying codes, text and illustrations. The design of the web site also allows other languages to be added simply to the library.

# 9. ICF PAPERS WELCOME IN THEMATIC ISSUE OF DISABILITY STUDIES QUARTERLY

This is a Call for Papers for a thematic issue of *Disability Studies Quarterly* to appear in Fall, 2004. The theme is "Disability Studies in Education of Public Health and Health Professionals: Can It Work for All Involved?" Whether "Disability Studies" as an academic field, conceived in opposition to the "medical model of disability," can retain its integrity in the context of health-related professional education is a contested issue. Conversely, from the Public Health sector's perspective, can Disability Studies be integrated into current curricula while maintaining the goals of public health, is another question. Meanwhile, several innovative programs are in fact introducing the "social model of disability" and its implications into the curricula of various health and public health professional schools and programs. This thematic issue of DSO seeks papers that both describe such programs and reflect on the controversies they engender. See DSQ's website (www.dsq-sds.org) for guidelines regarding different types of submissions. The deadline is June 30, 2004, for papers that will be sent for peer review. The deadline is July 15 for Commentary (not peer-reviewed). It will be extremely helpful if you indicate as soon as possible your intention to submit either kind of paper. Please send expressions of interest, or questions, to Guest Editor Kristine Mulhorn, Ph.D., at kmulhorn@umflint.edu.

## 10. THREATS HEADS ADVOCACY AND REIMBURSEMENT COMMITTEE OF ASHA, INCLUDES ICF GOAL

Travis Threats recently visited AHSA Headquarters as Head of the Advocacy and Reimbursement Committee of the Special Interest Division of ASHA having to do with intervention with persons with neurogenic communication disorders. As part of their three year strategic goals, there is one goal on educating the profession and the public about the ICF philosophy of treatment, i.e., that communication is not just a goal in and or itself but also to help larger major life areas such as attenting church, participating in leisure activities, political rights, etc. For more information, contact Dr. Threats at: Travis T. Threats, PhD, Associate Professor, Saint Louis University, 3750 Lindell Blvd.,

McGannon Hall, Room 14, St. Louis, Missouri 63108 tel 314-977-3175, threats@slu.edu.

### 11. AURA KAGAN WINS \$376,998/3 YEAR GRANT ON APHASIA, INCLUDES ICF

Aura Kagan, Ph.D., a speech-language pathologist, has just been awarded a grant for a project entitled: "A participation-based framework for outcome measurement in Aphasia Institute" by the Ontario Ministry of Health and Long-Term Care Grant # 06021. It is a three-year grant for \$376,998. She is using various frameworks including the ICF for this work, and Travis Threats is the ICF consultant on this project. Dr. Kagan is the Executive Director, Director of Education and Applied Research at the Aphasia Institute - The Pat Arato Aphasia Centre. This is a highly innovative nonprofit organization that has always had at the forefront of its mission the quality of life of persons with aphasia via improving their ability to successfully interact with their environment. The web site for the center is <a href="www.aphasia.ca">www.aphasia.ca</a>. For more information, contact Dr. Kagan at The Aphasia Institute, 73 Scarsdale Road, Toronto, ON M3B 2R2, Canada, Akagan@aphasia.on.ca, Tel: 416-226-3636, x24, Fax: 416-226-3706.

## 12. "NACC CLEARINGHOUSE ON ICF" IS HOTLINKED ON WHO WEBSITE http://www.who.int/classification/icf

This "NACC Clearinghouse on ICF" is a "Related Link" on <a href="http://www.who.int/classification/icf">http://www.who.int/classification/icf</a>. The <a href="www.icfconference.com">www.icfconference.com</a> website for the Halifax conference is also a "Related Link". Visit the WHO website often for updates. And catch up on all the Monthly NACC Clearinghouse on ICF Messages since October 2002 at <a href="www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm">www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm</a>. There are now 600 subscribers to the "NACC Clearinghouse on ICF".

#### 13. SPOTLIGHT ON JOHN CREWS

John E. Crews, D.P.A. is the new the Lead Scientist with the Disability and Health Team in the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. His Doctorate of Public Administration is from Western Michigan University, Kalamazoo, Michigan, in 1990, where he was honored as "All University Graduate Research and Creative Scholar" in 1988. John has over twenty-five years experience in vision rehabilitation and disability research. He managed a clinical program for older people with visual impairments for fifteen years in Michigan until 1992. He then became the Acting Director of the Rehabilitation Research and Development Center on Aging at the VA in Atlanta. After that, he served as the Executive Director of the Georgia Governor's Council on Developmental Disabilities, and then served as Research Director at the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University. In 1998, he joined the Centers for Disease Control and Prevention in Atlanta. John's specialty is vision impairment and aging. He serves on several boards, including the American Foundation

- for the Blind, American Society on Aging, and Lighthouse International. John's wife, Nancy, is a social worker, and his daughter, Kate, is a junior at Agnes Scott College in Atlanta, majoring in French education. John says: "ICF is the currency for our research...ICF is a Swiss army knife...ICF is the conceptual framework applied to my analyses of how vision impairment relates to activities and participation..." John has 17 ICIDH and ICF publications to his credit, including:
  - Hendershot, G. E. & Crews, J. E. (in progress). International Comparability of Survey Statistics on Visual Impairment. <u>Journal of Visual Impairment and Blindness</u>.
  - Crews, J. E. & Campbell, V. A. (in press). Effects of Multiple Health Conditions Upon Function Among Older Visually Impaired People.

    <u>Proceedings of the 2002 International Conference: Developing and Delivering Quality Services for Frail Older Blind and Partially Sighted People</u>. London: Royal National Institute of the Blind.
  - Crews, J. E. & Campbell, V. A. (in press, expected May, 2004). Vision Impairment and Hearing Loss Among Community Dwelling Older Americans. <u>American Journal of Public Health</u>.
  - Crews, J. E. & Smith, S. M. (2003). Public Health and Aging. <u>American Journal of Public Health</u>, 93, 700-702.
  - Crews, J. E. (in progress). Neither Prepared Nor Rehearsed: Caregiving and Disability over the Lifespan, A Public Health Perspective. In <u>Caregiving for Individuals with Disabilities</u>, ed R. C. Talley & J. E. Crews. New York: Oxford University Press.
  - Crews, J. E. (2003). The Role of Public Health in Addressing Aging and Sensory Loss. Generations, 27(10), 83-90.
  - Lollar, D. J. & Crews, J. E. (2003). Redefining the Role of Public Health in Disability. <u>Annual Review of Public Health</u>, 24, 195-208.
  - Crews, J. E. & Campbell, V. A. (2001). An Examination of Activity Limitations and Conditions Related to Vision Impairment in Older People. In H.-W. Wahl & H.-E. Schulze (Eds.), On the Special Needs of Blind and Low Vision Seniors: Research and Practice Concepts. Amsterdam: IOS Press.
  - Crews, J. E. & Campbell, V. A. (2001). Health conditions, activity limitations, and participation restrictions among older people with visual impairments. <u>Journal of Visual Impairment and Blindness</u>, 95, 453-467.

- Crews, J.E. & Long, R.G. (1997). Conceptual and methodological issues in rehabilitation outcomes for adults who are visually impaired. <u>Journal of Visual Impairment and Blindness</u>, March-April 1997.
- Long, R.G., Crews, J. E. & Mancil, R. (2000). Creating measures of rehabilitation outcomes for people who are blind and visually impaired: The FIMBA Project. <u>Journal of Blindness and Visual Impairment</u>, 94 (5), 292-306.
- Crews, J. E. (2000). Patterns of activity limitation among older people who experience vision impairment. In C. Stuen, A. Arditi, A. Horowitz, M. A. Lang, B. Rosenthal, & K. Seidman (Eds), <u>Vision rehabilitation: Assessment, intervention and outcomes</u>. Exton, PA: Swets & Zeitlinger.
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- Crews, J. E. (1996). Rehabilitation outcomes among older people who are visually impaired. In M. Gozovsky (ed.), People who are blind or visually impaired—a look toward the year 2000, (107-83). Proceedings, 27-28 February 1996, Kfar Hamaccabia Hotel, Tel Aviv, Israel: Israel Association of Education & Rehabilitation and Rehabilitation Center American Israeli Lighthouse.
- Crews, J. E. (1994). The demographic, social, and conceptual contexts of aging and vision loss. <u>Journal of the American Optometric Association</u>, 65 (1), 63-68. Reprinted in English and Hebrew in M. Gozovsky (Ed.), (1996). People who are blind or visually impaired—a look toward the year 2000. Proceedings. Tel Aviv, Israel: Israel Association of Education & Rehabilitation and Rehabilitation Center American Israeli Lighthouse
- Crews, J. E. (1991). Measuring rehabilitation outcomes and the public policies of aging and blindness. In N. Weber (Ed.), Vision and aging: Issues in social work practice, (137-151). New York: Haworth press. Reprinted in English and Hebrew in M. Gozovsky (Ed.), (1996). People who are blind or visually impaired—a look toward the year 2000. Proceedings. Tel Aviv, Israel: Israel Association of Education & Rehabilitation and Rehabilitation Center of American Israeli Lighthouse.
- Nieuwenhuijsen, E., Frey, W. & Crews, J. (1991). Measuring small gains using the ICIDH severity of disability scale: Assessment practice among older people who are blind. International Disabilities Studies, 13, 29-33.

TO OBTAIN REPRINTS OR INQUIRE ABOUT JOHN'S NEW GRANTS PROGRAM, CONTACT JOHN E. CREWS, D.P.A., Centers for Disease Control and Prevention, 1600 Clifton Road, E-88, Atlanta, GA 30333, Phone: 404-498-3013, Fax: 404-498-3060, E-mail: WZC0@cdc.gov

## 14. SHARE YOUR ICF NEWS ITEMS WITH EVERYONE, SEND NEWS TO PAUL PLACEK

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