

September 1, 2014

Lynne:

With Special Hope's support, this has been a fruitful and productive year for the Office of Developmental Primary Care. Our work is advancing. I wanted to update you on what we have accomplished and new directions moving forward:

Engaging and mobilizing diverse stakeholders:

1. **The Developmental Center closure process has moved into the implementation planning phase. Dr. Kripke will represent the Arc CA/ODPC in the implementation workgroup in Sacramento on September 10 and 11.** Because of our work, the recommendations are heavily weighted towards developing new health care resources in the community. Dr. Kripke has been laying the ground work to expand clinical services for those with complex needs moving from the developmental centers. In addition to the workgroup, Jim Shorter, Megie Okumura and Dr. Kripke had a productive meeting in Sacramento with the new Director of the Department of Developmental Services, Santi Rogers to advance the same goal.
2. **ODPC continues to collaborate regularly with the Autistic Self Advocacy Network.** This is a critical time for strong policy leadership. The Centers for Medicaid and Medicare Services is rolling out managed care. The new Home and Community Based Waiver definitions have many important implications for health service delivery which ASAN is well positioned to influence.
  - a. Secured a commitment from the Arc CA to put ASAN's Model Supported Decision Making Legislation on their docket and Medicaid access to early intervention. ODPC is working to build coalition.
  - b. Dissemination activities for *Our Lives, Our Health Care* paper and other work.
  - c. Regular collaboration on policy, priorities and messaging.
  - d. Research collaborations (AASPIRE, new center for Workforce Studies, PCORI grant).
3. **The California Academy of Family Physicians is collaborating on MediCal Access.**
  - a. A resolution "Monitoring and Ensuring Access to Care for Medi-Cal Beneficiaries" was presented to the leadership, membership and board. (disability emphasized)
  - b. Due to our educational work, disability access was highlighted in CAFP's lobby day.
  - c. CAFP's policy team is assisting ODPC and ASAN on a variety of issues such as the CART model, early intervention, supported decision making and access.
4. **Secured commitment to include DD as a topic, and submitted materials with national colleagues for the Society of Teachers of Family Medicine's new residency curricular project.** This will become the standard curricular resource for family medicine residencies.
5. **Working with Golden Gate Regional Center and documentary film maker, Mark Felgen, on video projects to explain the CART Model and community-based care. Also, Dr. Kripke appears in the new release of "Citizen Autistic" (William Davenport)**
6. **Dr. Kripke has been on the advisory committee for the Kaiser Autism research group. The descriptive paper on Autism and medical conditions is being written for publication now.**
7. **Dr. Kripke joined the advisory committee of the People with Disabilities Foundation.**

Deliverables, since October 2013:

1. **Two peer reviewed papers published:** These papers are unique contributions to the field because they provide clinicians with pragmatic guidance on applying social and neurodiversity models to clinical practice.
  - Kripke, C. C. (2014). "Primary Care for Adolescents with Developmental Disabilities." *Prim Care* 41(3): 507-518.
  - Nicolaidis, C., Kripke, C., Raymaker, D. (2014). "Primary Care for Adults on the Autism Spectrum." *Med Clin North Am* 98(5): 1169-1191.
2. **New Office of Developmental Primary Care Website:** The Office of Developmental Primary Care launched a new website [odpc.ucsf.edu](http://odpc.ucsf.edu) with new logo, accessibility features, and updated, revised and expanded content including:
  - Updating the content of all documents
  - Two new sample lectures
  - "What I Wish My Doctor Knew About People Who Accompany Us to Our Medical Appointments"
  - Bibliography of sexuality resources
  - A translation of Evaluation of Behavior Change into Spanish
  - Exercising rights with health plans—Timely Access
  - The website receives >100,000 hits per year
3. **Training for 803 people in 11 separate training forums.** We have two more trainings scheduled before the end of the project. We have been reaching the target audiences:
  - Caregivers 111; UCSF faculty 88; Other practicing clinicians and faculty 215; Self advocates 60; Health Professions Students 210; Other 115
4. **Medical Student Elective in Developmental Medicine receives high ratings.** Through it, we continue to engage a broad range of self advocate, parent and clinician preceptors.
  - 11/15 students have completed the elective and we have several more scheduled before the end of the project.
  - Students provide 15 health education classes for self-advocates per year.

Future Directions:

- ODPC is in negotiations with Golden Gate Regional Center to establish a new primary care clinical service at UCSF. The group home, primary-care service is growing
- ODPC is developing new collaborations with Green Mountain Self Advocates. Dr. Kripke will present with Max Barrows, Nicole LeBlanc and Ari Ne'eman at the Self Advocates Becoming Empowered conference in Oklahoma in October. Vermont is implementing single payer health system which is an opportunity to do systems work with GMSA in health policy.
- Mark Felgen and ODPC are also working on training videos and have secured partial, private philanthropy to support that effort.