Part 1: Symposium Overview

The Special Hope Foundation convened a symposium on Friday September 25, 2015 on Effective Healthcare for Adults with Developmental Disabilities. Nearly 100 health care professionals and disability rights program advocates and experts met to discuss health care services and the opportunity to create a more effective system of care within a managed care context.

The Symposium was held at the California Endowment in Oakland, California and featured key note presentations by Dr. Kevin Grumbach, the Chair of UCSF Department of Family and Community Medicine; Jennifer Kent, Director of the California Department of Health; and Ari Ne'eman, the President and Cofounder of the Autistic Self Advocacy Network. The Symposium was moderated by Kayce Garcia Rane, a strategic planner with expertise in helping communities identify and implement cost-effective strategies to improve access to health care services for underserved populations.

The early morning presentations provided background information on the current state of health care services for adults with developmental disabilities. Speakers also used their presentation time to engage with symposium participants directly. Out of these key note discussions several key questions emerged that would influence the remainder of the day:

- How can we "tip over" the model of health care services so that we have a greater focus on earlier, more proactive and cost-effective interventions?
- How can we best leverage the fractured resources of the current system of care and what policy changes are needed to use existing resources more efficiently?
- What health care outcomes do we want to achieve and how can we ensure that it is these outcomes that we use to measure success, as opposed to the number of units provided?

Following the first presentations, a panel of individuals shared models of effective health care practices and discussed the ongoing challenges faced by adults with developmental disabilities.

- Athena Chapman reviewed the opportunity for health care reform under the Affordable Care Act and the entry of so many Californians into managed care health plans.
- Elizabeth Grigsby shared her experiences as an adult with developmental disabilities in accessing routine and emergency health care services and how lack of training and awareness on the part of care professionals resulted in an exacerbation of symptoms and the onset of new health challenges.
- Clarissa Kripke provided an overview of the CART model as a strategy for redesigning health care services for adults with developmental disabilities and discussed the potential implications for statewide expansion of the newly launched pilot site at UCSF.
- Mary Lou Breslin reviewed the priority areas for managed care policy and practice reform and introduced additional model programs in Grass Valley, Berkeley, and San Diego.

Afternoon sessions included break out groups on critical topic areas, followed by a report out of recommendations and opportunities for action.

Discussion Topics:

- Managed Care Agendas & Priorities
- Public Communication, Advocacy, and Education
- Provider Training
- Transition Issues
- Needs of Dual Eligibles with Developmental Disabilities
- Role of Care Coordination
- State and Local Policies
- Supported Decision Making
- Future Health Research Priorities

A detailed summary of the key recommendations and opportunities for action that emerged from each discussion group are included in the Appendix.

Part 2: Major Discussion Themes

Discussion throughout the day and in the breakout groups focused on several major themes:

1. Public Education, Policy Making, and Advocacy Work
2. Health Care Service Delivery System: Provider Training and Program Practices
3. Use of Research and Data to Inform Practice Changes

The following summary of the recommendations and directions that emerged from the symposium is extracted from the breakout group session notes, the report-outs from the sessions, and the overall conversation throughout the day.

Public Education, Policy Making, and Advocacy Work

A major component of the work is shifting public perception of individuals with disabilities. Symposium participants made a number of recommendations about changing knowledge and understanding of all individuals, recognizing that we all have a responsibility for recognizing equity issues for individuals with disabilities and a voice (or at least a vote) in making social and policy improvements.

- Address stigma and bias regarding the capacity of individuals with developmental disabilities to live independently. Create sample protocols, policies, or informational guides for *both* daily living and safety net providers on how to work with and interact with people with disabilities that provides supported assistance and dignity. Consider public service announcements. Consider partnerships with health plans to discuss how we are changing the way we operate. Consider leveraging the "aging of baby boomers" as a model to spur thought and discussion; recognizing that more adults are entering their later years of life with physical limitations.
- Create opportunities for shared learning amongst similar organizations who are working towards shared goals. Develop methods (articles, smaller collaborative meetings, e-mail blasts, etc.) to disseminate what works and how to create culturally and accessibly welcoming spaces and services. Engage DSS or other frequently visited web site as a hub for information, targeting (1) adults with developmental and other disabilities; (2) family members and support allies; and (3) health care providers.
- Advocate to key public institutions, health care plans, and providers for the inclusion of more adults with developmental disabilities on advisory boards and commissions. Review history of the

Disability Rights movement and model of the Mental Health Services Act in placing consumers of public mental health services at the center of policy making for the State of California.

- Provide public education and outreach on the statewide policy and advocacy agenda. Support distribution of legislative platform and hold forums to discuss implications of proposed policies. Specific policy recommendations that emerged from the days discussion, include:
  - Address billing rate structure. Need for billing codes that allow for (1) extended discussion with individuals with verbal communication challenges (2) out-of-area transportation to and from health care services (including wait time during appointment(s).)
  - Competency and transition policies. Need to create medical policies that create transition planning structures for youth and their families to transition to the adult health care system starting around age 14. Need to create medical policies that shift primary mode of communication from individual only to individual with consented supporting decision-makers and establish protocols on how to adopt procedures.
  - Define case coordination as a Medi-Cal and/or Medicare eligible activity. Create a reimbursement rate structure that compensates health care providers for the use of paraprofessionals in case coordination. (See current efforts by DHCS to create a peer certification program, background research on mental health model can be viewed at: http://www.dhcs.ca.gov/services/MH/Documents/CMHPCPeerCertPaper2015.pdf.)

Health Care Service Delivery System: Provider Training and Program Practices

Strengthening the health care delivery system was the biggest topic of conversation. Symposium participants made a number of recommendations on how health care systems can improve care to adults with developmental disabilities. Recommendations were generally structured around three main categories: (1) health system policies and procedures; (2) provider education and training; and (3) clinical practice and approaches to service delivery.

- Create a dialogue between health care plan providers and adults with developmental disabilities on existing strengths and challenges in accessing high quality and effective health care services. Focus discussion on strategies to “tip” the model, resulting in more preventative health services and fewer emergency room visits and lengthy treatment stays. Promote the use of pilot studies to demonstrate cost savings *and* health outcomes. Include social determinants such as quality of life in the study to better incorporate the impact of whole person wellness into health outcomes.
- Create physician and medical provider pathways to encourage training and expertise in working with adults with developmental disabilities. Advocate for the inclusion of more curriculum within institutions of higher education about the health care needs of adults with developmental disabilities. Create collaborations between university faculty and the community to create education curriculum. Convene higher education summit to share findings and recommendations with department heads and faculty for community college EMT, nursing, and other training programs for health professions.
- Create more awareness of the linkages between physical and mental health for adults with developmental disabilities, including the higher incidence of serious mental illnesses associated with

some diagnosis for developmental disabilities (e.g. autism). Promote research that supports the inclusion of individuals with developmental disabilities as a designated underserved population. Create workshop group at annual behavioral health conferences (see the California Institute for Behavioral Health Solutions www.cibhs.org).

- Develop information briefs and fact sheets on supported decision making. Create a brief education/training toolkit for health plan networks and physician associations to roll-out to their health practitioners in brief continuing education presentations. Provide sample tools and protocol worksheets on shared decision-making practices.
- Develop information briefs and tip sheets on Medi-Cal and Medicare billing practices for physician groups on how to receive reimbursement for communication time, care coordination, and other good practices for working with adults with developmental disabilities (Include also tips for dual eligible "medi-medi" individuals.) Provide examples of acceptable documentation for billing notes for physicians and other health care practitioners.
- Develop individual- and family-friendly information briefs and tip sheets on expectations in service for health delivery and care coordination for physicians to share with individuals, family members, or support allies.

Use of Research and Data to Inform Practice Changes

Too often data associated with services for adults with developmental disabilities counts and measures how many units of services are received without any true connection to how well individuals are doing. Symposium members discussed the importance of developing measures to hold health care payor plans and medical practices accountable for improving the overall well-being of individuals with developmental disabilities.

- Develop and measure patient reported outcomes associated with quality of life, including specific home, person, and environmental metrics, for example:
    - ▪ The extent to which adults with developmental disabilities are living independently in a place of their own choosing and are productively engaged in meaningful work or education pursuits.
    - ▪ The extent to which adults with developmental disabilities are optimistic about their own health and wellbeing, recognizing that their bodies have a normal baseline that they want to maintain and stay healthy within.
    - ▪ The extent to which adults with developmental disabilities report that they have good access to the supports of daily living (e.g. healthy food options, transportation, whole-person wellness and preventative health care services).
- Create better, diagnosis specific, measures of generally expected client outcomes by which to measure the success of health care services and interventions. Create standardize process by which to measure overall improvements or maintenance of health and wellbeing within the primary care setting.
- Evaluate physician training programs to determine whether physician education and training is having any measurable impact on (1) self-described capacity of general practitioners to provide routine and preventative health care services for adults with disabilities; (2) the number of

practitioners identified by health plans as having expertise for their plan members with developmental disabilities; and (3) the extent to which adults with developmental disabilities perceive that there are sufficient numbers of well-trained medical providers to treat their (primary) health care needs.

- Create research partners to prepare papers on studies and findings. Create dissemination plan that includes national medical associations, academic medical centers, and at national conferences.
- Engage Regional Centers as advocates for ongoing research studies to provide existing data and help facilitate access to clients and informed research subjects.
- Advocate for national policies regarding state and regional reporting to include outcomes for individuals with developmental disabilities (beyond units of service). Work with individuals and health research partners to develop recommended list of outcomes.

Part 3: Summary and Next Steps

The Special Hope Foundation convened this Symposium for the purpose of creating a dialogue between health providers and advocates and providing opportunities for increased communication, shared learning, and collaboration (Special Hope Foundation, strategic plan Approach # 5). During the final report out session several individuals indicated that they were leaving the symposium with their own personal set of next steps and action items, others were exchanging phone numbers and discussing opportunities for ongoing partnerships; clear indications of the success of the symposium to meet the Foundation's internal objectives.

For the Special Hope Foundation the same opportunity exists to conclude the Symposium with some next steps and action items. The following recommendations emerged from an analysis of the day's discussion.

1) Identify pivotal policy and practice changes. Create funding opportunities for self-advocacy networks to develop advocacy pieces and share messages with policy makers. (Approach #1)
2) Identify pivotal knowledge and practice changes for healthcare providers. Create funding opportunities for health (and behavioral health) professionals and research institutes to raise awareness, knowledge, and competencies in best practices amongst their peers. (Approach # 2)
3) Identify pivotal research recommendations and informational briefs. Consider funding opportunities to develop informational materials and disseminate appropriately. (Approach #3)

Video Project

The Special Hope Foundation will also be preparing two video pieces to serve as a catalyst ongoing engagement and collaboration. It is proposed that one video will be geared to health care professionals and another will be geared to policy makers. While many ideas and themes emerged during the day, the following encapsulates critical messages for health care providers, policy makers, and funding partners voiced by symposium participants:

For health plan managers, physicians, and other health care providers…

There are easy and effective practices that health care systems can adopt to provide health care services to adults with developmental disabilities. These models and practices will reduce costs and increase patient health and wellbeing. Unfortunately too few health providers are aware of these practices or self-identify as competent in treating adults with disabilities. As a result, individuals are not receiving high quality primary health care services and too many individuals receive their primary health care services within the specialty or emergency care system. It is imperative that we provide more opportunities for health care providers to raise their own skills, confidence, and competencies to treat adults with developmental and other disabilities within the primary care setting. *Join the Special Hope Foundation and our partners in tipping the model to create more effective health care solutions….*

For policy-makers and health foundations…

Our world is richer through the inclusion and full participation of diverse individuals. Now with the implementation of the Affordable Care Act we have an opportunity and an imperative to enable individuals with developmental and other disabilities to manage their own health care needs and have equitable access to primary and preventative health care services. We need to create a framework for health equity that is rooted in the voices of the individuals receiving care, and grounded in clear and measurable data pertaining to a holistic understanding of health and well-being. *Join the Special Hope Foundation and our partners in tipping the model to create more effective health care solutions….*

> *All you had to do was listen to me. I know my body better than anyone. Listen to us whether we are verbal or non-verbal. We CAN tell you things if you just listen; it's not rocket science.*
>
> - *Symposium Participant*

Part 4: Appendix A - Discussion Group Report Out Notes

The discussion group report-out notes were transcribed to the best of our ability. Please be aware that there were rich conversations within each discussion group that may not be fully reflected in these notes. The notes are provided as a way to help participants recall their discussions and reflect on their own engagement with the day's activities.

Managed Care Agendas & Priorities

How can health plans prioritize improving healthcare services for adults with developmental disabilities on their agendas, initiatives, and areas of focus?

Notes:

Recommendation	Opportunity
Expand understanding of Managed Care to all Stakeholders	- Community forums - Public Service Announcements - Include Health Care Plans
Enrich understanding of what each other does	- Smaller collaborative meetings among and between Agencies
Enhance adequacy of Provider Network	- Rate Structures - Tele-Med and Virtual - Creative tuition reimbursement

Next Steps:

Name	Organization	Action

Public Communication, Advocacy, and Education

How can we educate, advocate, and publicize the issue of healthcare services for adults with developmental disabilities to the public and media? Who is the audience we want to target?

Notes:

Recommendation	Opportunity
Coordinate development of plain language health care materials	- For Individuals - For Health Plans - For Providers - For Public
Identify effective methods to <u>disseminate</u> information	DSS has a hub of information, (or housed in more publicly accessible place) Engage in health care coalitions Integrate out – (reverse integration)
Health care plans need to include people with Intellectual and Developmental Disabilities at all levels of information development Prevention through Education Intellectual and Developmental Disabilities part of development and testing	Disability Advisory Committees, Boards Create inclusive communities and local support. Efforts must be on-going Go Viral – one million hits a day!

Next Steps:

Name	Organization	Action
Get Grant: Search nation for best plain language materials. Update and disseminate to all states, health plans, teaching hospitals, medical schools, and individuals.		

Provider Training

What are ways providers can improve the way they treat adults with developmental disabilities? What are providers' training and education needs?

Notes:

Recommendation	Opportunity
Early Career Training – Never too early to start, and develop a career pathway in disability	115 Waiver Collaboration with University / Community Program
Integrated Mental Health and Developmental Disability Training including behavioral supports Contact Experts – Train Trainers Community Outreach	Behavioral Health Integration Coalition of PC / Mental Health Telemedicine and e-consult models
Building and sustaining Education Champions Training sessions for staff as well as faculty	Champions: Regional Center ODPC UCR

Next Steps:

Name	Organization	Action

Transition Issues

What are the unique healthcare needs and issues facing youth with developmental disabilities and how can providers serve them better?

Notes: Transition to Adult Life Living

Recommendation	Opportunity
Evidence based mixed methods approach. Quantitative, Qualitative statistics base on real, lived experiences.	Meaningful research Evolving federal policy that could be used to support outcomes
AAMC include specific numbers of required hours spent in under graduate and graduate in developmental disabilities and associated special needs	Medically underserved population for purposes of funding. - Incentivize a percent of patents with disabilities receiving care
Collaboration between Department of Education and Department of Social Services ------------------------- Move Consent age to 18 years	

Next Steps:

Name	Organization	Action
		Health plans include transition process as a mandate. “Patient Navigators” Primary Pediatrician Physician starts transition discussion at age 14

Needs of Dual Eligibles with Developmental Disabilities

Dual Eligibles are typically 'high users' of healthcare services with multiple chronic conditions and disabilities. What are the unique healthcare needs and issues facing the older population of adults with developmental disabilities?

Notes:

Recommendation	Opportunity
- Supported Decision Making - Outreach to Medical Providers regarding planning tools and options	- Listen to the families and individuals receiving the support - Billing structure that supports listening
- Supports are decreasing (caregivers) as the need increases and people age - Proactive Planning to match the needs with natural community resources	- Provider Training
- Medical Care Coordination: - Educate families/ caregivers regarding Medi-Cal / Medicare services	

Next Steps:

Name	Organization	Action

Role of Care Coordination

With care coordination offered as a service in many managed care health plans, how will Care Coordination improve healthcare for adults with developmental disabilities? In what ways are care coordinators familiar with the needs people with developmental disabilities?

Notes:

Recommendation	Opportunity
Conduct an environmental scan that identifies the landscape and ecosystem	Reform, change, innovation happening Landscape of intellectual and developmental disabilities changing
Define case coordination and mandate a single point of entry that provides in-and-out patient Culturally competent certified care coordinated	Integration is changing Mandate from CMS
Evaluate and measure	

Next Steps:

Name	Organization	Action

State and Local Policies

At the local and state level, what are some changes in policies that can improve the delivery of healthcare services for adults with developmental disabilities?

Notes:

Recommendation	Opportunity
Get rid of carve outs "Carve In" Person centered plans	Eliminate 3-5 years Make outcomes 7-10 years BHS/CCS/etc.
Consistency across state ie) Knox Keene counties RCS	Integrative look at people Kaiser Model
Funding: Eliminate SNF -> fund other alternatives Eliminate duplicative assessments Single payer system	Least restrictive setting Person Centered care IHSS / RCS

Next Steps:

Name	Organization	Action

Supported Decision Making

What is the role of supported decision-making in empowering adults with developmental disabilities to advocate for themselves regarding their healthcare decisions?

Notes:

Recommendation	Opportunity
Presumed incompetence for all individuals - Patient Education	Equality in Treatment
Medical Community Education – What is SDM? How is it useful?	Greater Patient Control
Standardized patient profile for use in SDM, includes identified decision makers	Legit supported decision making teams.

Next Steps:

Name	Organization	Action
Susan Mizner	ACLU	Finding out from lawyers for med providers
Trudy Grable	PHP	Fears of not having conservator by parents

Future Health Research Priorities

Where are the gaps in knowledge? What is known and what needs greater inquiry in regards to primary and specialty care for adults with developmental disabilities?

Notes:

Recommendation	Opportunity
Define Health for IDD and develop measures: - Quality of Life – Family - Social determination of health - Scale of Metrics - Quality of care	- NQF - HEDIS - NCQI - National Care Indicators - US Prevention Task Force
Study Models in existence - Look at current models - Develop new models	Current Models - Westside "achievable" - CART - HER - Centers for Independent Living
Study Develop / Provider Education Models (physician / care provider) - -Cultural Competency - IDD Specific Needs - -Show improvement in health outcomes based on education	- Health Plans - Academic Medical cCenters - National Conferences/Grand Rounds - Regional Center - Webinar

Next Steps:

Name	Organization	Action
Megie and Alecia	UCSG / Westside	Look at testing Mental Health Metrics
Lisa	Kaiser	Pilot Metrics