IACC Services Subcommittee
DRAFT Services Workshop Notes for Members to Inform the Services Strategic Plan – Prepared by Cathy Rice

IACC Research Strategic Plan	IACC Services Strategic Plan
Core Values	**PROPOSED** Core Values
Sense of Urgency	*Sense of Urgency*
Excellence	*Maximizing Quality of Life*
Spirit of Collaboration	*Self-Determination*
Consumer-focused	*Consumer-focused*
Partnerships in Action	*Partnerships in Action*
Accountability	*Access to Supports*
Cross-cutting Themes	**PROPOSED** Cross-cutting Themes
Heterogeneity	*Individual First*
Prevention	*Reduce Limiting Symptoms, Increase Strengths*
Earlier Detection	*Community Inclusion*
Lifespan Perspective	*Lifespan Perspective*
Datasharing	*Coordination of Supports*
Resources	*Access to Resources and Supports*
Public-private Partnerships	*Public-private Partnership*
Community Engagement in ASD Research	*Individual, Family, and Community Engagement*

How to organize the IACC Services Strategic Plan Goals? 3 options for discussion

1. 6 priority areas From RFI	2. The earlier IACC Services Roadmap was built around the six performance measures of the President's New Freedom Initiative (NFI):	3. Model after IACC Research Plan with DRAFT EXAMPLE Questions:
- Adult - Community - Family Support - Early Intervention/school services - Providers - Infrastructure - Other areas - Employment - Evidence-based services - Health and Safety - Early Diagnosis and Treatment - Transition to Adulthood - Therapies	- Family and professional partnerships; - Early and continuous developmental and medical screenings; - Availability of all needed health, education and social services; - Organization of community-based services for easy use: - Effective youth transition to adult services, work and independence; - Access to adequate public/private insurance or other financing mechanisms	- How do we know what is going on? - How do we get the support we need for learning? - How do we stay healthy and safe? - How do we have support for family and community? - How do we access quality services and supports (learning, self-help, play/recreation work, residence, etc.)? - How do we get services and supports from well-trained providers? - How do we pay for services and supports?

Also consider Federal agency impacted by each potential recommendation

Proposal: For the November 8th IACC Services Workshop, the Services Subcommittee Members should listen to each talk and think about the following issues:

Topic: Intro Session: Where We are Today & Where We Want to be in 10 years
Speaker(s): Nancy Thaler, Bill East, Charlie Lakin
Goals this topic addresses: Infrastructure   Family and Professional Partnerships   Organization of community-based services for easy use
Opportunities: • State DD systems have provided services for individuals with ASD under Intellectual Dis (MR) or Mental Health services.   • Reduction of individuals with DDs living in institutions.   • Research on evidence-based interventions getting more priority.   • Technology (websites with practice info and personnel prep www.learningport.us www.personnelcenter.org). Tech tools for teaching.   • National Core Indicators (www.hsri.org/nci/) indicate people with DDs report positive life quality when living with family members or in smaller housing settings with support.   • Costs for family-based housing and community supports lower than institutions.
Challenges: • Service systems inadequate to serve needs of individuals with DDs and do not truly incorporate ASDs.   • More individuals with DDs living at home.   • Research done in ideal circumstances and not evaluated in real-world settings or translated for practice.   • Accessibility of information and technology.   • Medicaid is the principal funding source for long-term DD services.   • In State DD systems, most people with ASD identified in 18-29 age group indicating increasing long-term adult service needs for this population. Population needs for long-term services is increasing greatly (general pop aging and DDs). We are facing a 2005 Medicaid budget for much higher 2012 demand (see CL slides). "the cliff" For Districts who put ARRA funds into personnel, not able to maintain.   • Even with recovery funds (ARRA), states have cut personnel to provide services and manage the development of new services.   • There is not a Federal Agency to train, support, and give policy guidance to State DD Programs (CMS – main one according to NL).
Policy Recommendations: • Integrate ASDs into DD state systems (Dev Dis), particularly for adult services and supports.   • Resources directed at family and community supports (see NT slides 29-31).   • Community supports to coordinate care across systems (home, community, school, employment, community) across all ages.   • Emphasize applied research and rapid, accessible translation to practice.   • Integrate ASD and DD needs in proposed policy and legislation changes.   • Create a DD services and supports website which incorporates and updates the best info on evidence-based practice, practice guidelines and resources.   • Need urgent attention to putting efficient, community-based funding and supports into practice.

- State DD Programs need a Federal home for coordination, training, model development and implementation.
- Need cross-level (local, state, fed), agency (ed, Medicaid, private), and community (indiv, family, community, service providers, agency) coordination to create an efficient, coordinated service system.
- Period of crisis is transition from Education to adult DD services (link systems to stop gaps in supports, identify seamless eligibility guidance).
- ASD Service and support recs need to be couched within the bigger system of other health and human long-term service needs (DDs in general, at the least, but consider overlap with mental health, substance abuse, elder care, long-term disability, preventative health care).

Topic: Self-Direction (Self-Determination)	
Speaker(s): Michael Head, James Conroy	
Goals this topic addresses:	
Organization of community-based services for ease of use	
Opportunities:	
• Successful models using Self-Determination (person-centered planning and Funding for services and supports). Michigan example of using Medicaid funds with consumer participation and control.	
• Look to model of some IDEA Part C programs which allow for service coordination as a service, multiple funding sources, coordinated tracking of services, goals, outcomes (ex. UT EI data system), and transition to Part B services.	
Challenges:	
• May not be cost savings – with same dollars, aim to support better lives and better outcomes.	
• Access to and coordination of multiple funding streams.	
Policy Recommendations:	
• Facilitate options for Self-Determination for adults; family-centered planning for children.	
• Create an over-arching DD / MH services and systems support through CMS?? which acts like Dept of Ed and IDEA for education, only broader for service coordination and tracking (vocational, housing, health, etc.). Look to model of some IDEA Part C programs which allow for service coordination as a service, multiple funding sources, coordinated tracking of services, goals, outcomes (ex. UT EI data system), and transition to Part B services.	

Topic: Standardized Assessment	
Speaker(s): Donald Clintsman	
Goals this topic addresses:	
Infrastructure	
Evidence-based services (assessment and outcomes)	
Organization of community-based services for easy use	
Opportunities:	
• Washington State DDS Model for DD services assessment and tracking system (Support Assessment, Service Level Assessment , Individual Support Plan). Common data collection, eligibility determination, path for paid or no-paid services.	
Challenges:	
• Multiple funding streams, need greater than resources, state and local development of systems	

in isolation.
Policy Recommendations:
• Create IDEA-like DD services and supports eligibility, supports, and outcomes system. More holistic approach to create an Individual Life Plan (ILP) across the lifespan (like an IEP or IFSP). • Develop and make available DD (MH) service coordination etool with designated Federal oversight (CMS?) and input from state DDS systems.

Topic: Prevention and Reduction of Seclusion and Restraint
Speaker(s): Kevn Ann Huckshorn
Goals this topic addresses: Evidence-based services Health and Safety Providers Workforce Development
Opportunities: • There have been several developments to reduce seclusion and restraint in intervention/education settings, including a GAO Report for Congress (1999). • SAMSHA supported project to understand seclusion/restraint reduction and best practices. Six Core Strategy Interventions developed to reduce s/r.
Challenges: • Personnel retention and procedures to keep clients and staff safe.
Policy Recommendations: • Systems of care should develop a prevention-based approach integrated into the vision and promoted by leadership. Determine how to adapt 6 Core Model to other systems such as educational settings and people with ASD, in particular. • Workforce development needs to include training and support for prevention techniques and reduction of s/r. • Integrate putting person safety and teaching proactive safety management as part of larger efforts for Safety (wandering, safety plan, prevention, community education, alert response, seeking help, first responder training).

Topic: Direct Service Workforce Training
Speaker(s): Carrie Blakeway, Erika Robbins
Goals this topic addresses: Workforce development
Opportunities: • In a time of a need for new jobs, there is a demand for long-term care service and support workers. • Models of workforce training requirements exist for other careers. • Department of Labor announced voluntary apprenticeship program for Direct Support Professionals (www.doleta.gov/oa) • Ohio identifying "Core Competencies" of the Unified Direct Service Workforce across multiple agencies / needs (DD, mental health, nursing care) through a Health and Human Service Lattice. • National Direct Service Worker resource on web http://www.dswresourcecenter.org/tiki-index.php

• Money follows the person through CMS offer an opportunity for innovative use of funds for coordinated workforce development.
Challenges:
• Complex supports Long Term Services and Supports workforce (direct support, informal support, paid support).
• Demand growing, supply not. Challenging jobs with low wages and few benefits. Little training, high turnover.
• Training fragmented to apply to specific populations (age, disability type, etc.).
• Minimal federal training requirements (only CNAs and Medicare Home Health Aids); variable state requirements.
• Funding, services, and workforce come from multiple programs with separate funding streams.
Policy Recommendations:
• Support Home-Community Based Service (HCBS) programs with quality training. Improve mechanisms to pay for training through CMS.
• Strengthen partnerships between DHHS and Labor on workforce development.
• Provide access to quality training and ongoing development opportunities.
• Take a holistic approach to workforce training by identifying core standard which apply to multiple populations who need community-based services and supports.
• Establish federal training requirements for LTSSW and establish minimal core standards as well as development training curriculum and career path (increase pay based on achieved competencies and complexity of work assignment).
• Identify models of states who have been able to develop and fund collaborative, cross-agency, cross-discipline workforce development and make this information readily available to all states.

Topic: Housing Options
Speaker(s): Sheldon Wheeler, Joseph Wykoski
Goals this topic addresses: Housing   Organization of community-based services for easy use   Meaningful outcomes
Opportunities:
• Olmstead Decision forcing housing change for people with disabilities.
• Fair Housing Act.
• Maine Shelter Plus Care Program – combines housing support with coordinated services for people experiencing homelessness with a disability or severe, persistent mental illness. Evidence of reduced service costs after housing support provided.
• Variety of housing options exist (examples from Oregon).
• Sec Sebelius noting that "home and a job" are important for health.
Challenges:
• Waitlist for Section 8 Housing often many years long and some states have stopped accepting applications. Limited resources.
• Unclear guidance of equitable housing access for people with disabilities?
• Challenges with having continuum of options and support opportunities hard to access or unavailable.
• Need to make sure there is basic quality and connection with rest of life, rather than quickly addressing all the numbers of people in need in a single issue manner (housing only).

Policy Recommendations:
- Include housing as a basic need in supports and services needed for people with DDs. Make "Disability" eligibility and opportunities clearly available on Hud website and in other Hud information.
- Identify and coordinate local, state, and federal resources to integrate housing support funding with other supports and services.
- Improve access to a range in housing options and funding to integrate into a person's Individual Life Plan (ILP).

Topic: Peer Supports

Speaker(s): Lisa Crabtree, Jim Sinclair, Julie LeBerge

Goals this topic addresses:
Community (Inclusion)
Therapies / supports

Opportunities:
- IDEA has indicated that education should take place in the "least restrictive environment" providing a shift in the inclusion of people with special needs in educational and broader communities.
- Research on education with peer models has shown positive impact on attitudes towards people with ASD and on life effectiveness (Towson State and Marshall model for college, PowerPals among others at school age, Walden/LEAP at preschool age).
- Models for Individual Life Plan exist such as PATH plan from Person-Centered Planning (http://www.ilr.cornell.edu/edi/pcp/index.html).
- National Council on Independent Living (http://www.ncil.org) and Centers for Independent Living (http://www.virtualcil.net/cils) support independence for people with disabilities.

Challenges:
- Outside of the educational setting, limited use of peer models and mentoring.
- Applied research needed on types of peer experiences [(goals, setting, peer (NT, ASD)], models, and outcomes.
- Experiences of people with ASD and their families have not been accessed to inform what is needed and what works.

Policy Recommendations:
- Consider inclusion of peer supports and mentoring in a person's Individual Life Plan (ILP)/PATH plan.
- Provide training, support, and evaluation for peer mentoring programs in more settings (colleges, secondary schools, employment).
- Consider how people with and without ASD can develop skills to be effective peer mentors.
- Focus on meaningful participation and opportunities in learning, living, working, leisure…

Topic: Systems Integration

Speaker(s): John Martin

Goals this topic addresses:
Organization of community-based services for ease of use

Opportunities:

• Models exist to help families and people with ASD find services in a more integrated manner (www.autism.ohio.gov).
Challenges:
• 4-6 State Department agencies (OH example) could touch the life of a person with a DD at different life stages. Confusing and challenging for families to navigate.
Policy Recommendations:
• Develop and support a services and best practice service portal at the Federal level, which links to state DD/autism resources such as the www.autism.ohio.gov website.
• For funding, planning, oversight, guidelines, etc. - Incentivize training, flexibility, lifespan, inclusion, long-term relationships, commonality with other DD needs, and integration of the person's whole life in developing person-centered services and supports.