

DS Imagine the Future Task Force
 April 28, 2014
 Comfort Inn & Suites

Meeting commenced: 1:00 p.m.

Members present: Bill Ashe, Anne Bakeman, Max Barrows, Nancy Breiden, Gail Falk, Camille George, Lisa Maynes, Ed Paquin, David Peebles, Susan Ryan, Karen Schwartz, Jennifer Stratton, Karen Topper, Marlys Waller, Theresa Wood, Susan Yuan, and Marie Zura

Members Absent: Linda Berger, Cheryl Phaneuf, Sr. Janice Ryan, James Smith, and Tracy Thresher

Staff and Guests: Rich Atkinson, June Bascom, Nicole LeBlanc and Kirsten Murphy

Focus #1 – Should Developmental Services be for adults only?

Age – Adults Only

| Positive | Negative |
|--|---|
| Trending that way now | Unknowns – don't know how it would play out |
| Focus DS expertise/funding on adults | Lose DS expertise |
| Schools and DCF are the lead child services | Lose continuity – another transition |
| Child services require specialized skills & networks | Don't trust schools & AHS |
| Fewer turf battles | Don't want to lose DD Act protections |
| Clarify school responsibility | |
| Increase advocacy to bring DS values to child services | |

Group A:

Facts

- If adult only services will probably be the same for kids because they come from DS providers.
- The DD Act actually does not protect kids from being restrained in schools.
- If IFS/DCF/AOE is lead, some feel they lack family centered approach. DD Act is family-centered approach.
- Most states definitions do not just include adults.
- For a new child who has needs like the 88 kids with DS waiver, what will they lose if we have an adult only program?
- Karen and Ann felt good about DAIL knowing their kids and could provide long term perspective.
- Having kids in DD Act there are less transitions – could lose continuity.
- Loose principles that say families should get services.

Group B:

- Clarity on restraints/seclusion is important.
- Concern regarding schools is big.
- “Cradle to the grave” system preferred.
- Level of expertise available? Hopefully will maintain and grow.
- Families need seamless process.
- Birth – 17 needs are different, but hard to define where/when ready. How to make smooth.
- The decision may be made for us, so good to advocate; that said, current system is better choice.
- Hard to have this conversation – should parallel federal definition.
- Hope = pool money – focus on needs of family.
- DS should maintain proper expertise.
- Ethical issue/decision – birth to death services better.

Group C:

Facts

- Move to separation of adults and kids services.
- Different “System of Care” for same aged kids (DMH, DCF, DDS, school/AOE) = values, what money pays for, eligibility/priorities, policies/guidelines.
- Creating a new cliff at transition age.
- Integrated Family Services (IFS) is eliminating Flexible Family Funding (FFF).
- Current Entitlement for kids = EPSDT and education; don’t cover services provided by DDS.
- Other systems don’t have quality review/expectations that are as rigorous as DDS (e.g., restraint)
- Dedicated focus of DDS on adults (if there is no need to coordinate with others on kids services).
- One less entity (DDS) involved with coordination of kids services.
- DDS favors adults (historically)
- DDS serves difficult kids that others don’t/can’t serve
- Age and DD diagnosis are not the only variable that indicates need for specialized knowledge.

Consensus

- No, but majority agreed on continuing to serve both kids and adults

Focus #2: How will we define Developmental Disability Services for the next 20 years?

1. Intellectual Disability Only

| Positive | Negative |
|--|--|
| IQ tests not subjective, not influenced by advocacy, have national standards | Excludes people who could benefit from DS |
| IQ tests not costly | IQ is an abstract measure. Doesn’t tell what a person can do |
| More people with ID could be served or get more | IQ misses environment |
| Closer to long tradition of DS, what we are good at | Better to have broad eligibility and limit services as necessary |
| Understandable by general public | Would need protections for currently served people with DD. |

2. Stay the same (Intellectual Disability & Autism Spectrum Disorder)

| Positive | Negative |
|--|--|
| We know the population | ASD costly to diagnose and subjective |
| WE know what we are doing | Unfair to others with IQ over 70 and similar needs. Favors one particular disability |
| Provide support to people with significant needs | DS providers lack skills/expertise to support people with higher IQ’s |

3. Adopt Federal Definition of DD

| Positive | Negative |
|---|--|
| Assessment is needs-based and points to services needed | Assessment is subjective based on reports of others with a stake in the outcome – Eligibility influenced by advocacy |
| Opens the doors to more people | Opens the floodgates – more people eligible and have to ration the same limited funds |
| More equitable – label isn’t really the important thing | More sensitive to environmental factors |
| More sensitive to environmental factors | Would shake up how services are delivered |
| Would shake up how services are delivered | |

Group A:

Positive

- With Federal definition we could target money better to those who need it.
- We may need a more objective tool for adaptive behavior.
- We do not like IQ tests.
- Good discussion.
- Interested in supporting people who have functional impairment.
- Can we keep what we have but lightening up on IQ. It should not be deciding factor.

Negative

- Can people in federal definition get services somewhere else?
- Social Security is based on functional impairment.
- Federal definition more matches what AOE does.
- Do we have capacity to assess those coming through the door that are not there now?
- How much time would it take to do an assessment of functional impairment?

Group B:

- Federal definition – we just don't have resources. More frustrated people.
- Question keeping people with ASD and not other disabilities.
- All agree on ID – IQ under 70. But concern that IQ is maybe not the most important thing. Prefer the idea of functional assessment (that is federal definition).
- Don't think ASD should be the sole impairment where people with IQ over 70 are eligible.

Group C:

Current

- Many people not eligible who have needs similar to people with PDD with IQ over 70.
- Serve people who are not in our area of expertise (e.g., Autism with mental health needs, Public Safety group, borderline personality disorder, DCF/Kids MH served until adult transition).
- Expectation we provide people with less services to get money for additional people.
- Services to people living with families is costing more today.
- Models that have worked well in past don't work for all today (e.g., shared living).
- Adaptive behavior eligibility can be gamed.
- Must re-determine eligibility after one year being out of services.

Consider

- Tier services based on eligibility? Separate level of services for IQ over 70 group.
- 3 areas of adaptive behavior to narrow door?
- Grandfather people in if changes made to eligibility

Consensus

- Adopt federal definition – No (general consensus)
- Change to Intellectual Disability (ID) definition only – Yes (general consensus)

Next Steps:

- **Subcommittee to meet in May to consider changes to DD Act**
- Ed Paquin, Susan Yuan, Marlys Waller, Gail Falk, Karen Schwartz , Nicole LeBlanc and Kristen Murphy
- **May 22nd meeting – 1pm – 4pm – Vermont Association for the Blind and Visually Impaired**
Agenda: Reports from subcommittees: Technology, Supported Living, Supported Employment
- **June 23rd meeting – 1pm – 4pm – Central Vermont Hospital**
Agenda: Report from DD Act subcommittee

Meeting adjourned – 4:00 p.m.