

Report on Focus Groups On Services for Residents with Developmental Disabilities and their Families

January, 2008

The Department on Disability Services, Management Advisory Committee (DDS MAC) Legislative Committee is serving as the steering committee for a District-wide initiative to rewrite the District of Columbia's laws governing services and supports for residents with developmental disabilities and their families.

During the months of September and October, 2007 the DSD MAC Legislative Committee held eight (8) focus groups to hear from individuals with disabilities, their families, service providers, advocates, and direct support professionals. A total of approximately one-hundred and seventy (170) individuals participated in the focus groups. Focus groups were in many cases co-hosted with other organizations, and were as follows:

1. Adults Focus Group: Project ACTION! (45 participants)
2. Adults, Youth and Direct Support Professionals Focus Group (48 participants)
3. Advocates Focus Group: Quality Trust for Individuals with Disabilities (12 participants)
4. Families Focus Group (13 participants)
5. Families Focus Group: HSC Pediatric Center, P.A.L.S. Group (16 participants)
6. Service Providers Focus Group: DC Coalition for Community Services (20 participants)
7. Youth Focus Group: Advocates for Justice and Education, Inc. (8 participants)
8. Youth Focus Group: National Children's Center Youth Empowerment Group (7 participants)

The purpose of the focus groups was to gather feedback on both general needs as well as specific areas of concern, including: the service eligibility process; assessment of individual needs; unmet service needs for individuals and families; the potential for expanding the populations served by the Developmental Disabilities Administration (e.g., expansions to serve children and/or a broader range of diagnoses); individual rights; grievance procedures, and court involvement in eligibility and services.

The DDS MAC Legislative Committee developed a list of standard focus group questions. However, due to time constraints and/or suitability, not every group was asked all questions.

The following report provides a group-by-group summary of the focus group questions and discussions.

The DDS MAC Legislative Committee thanks all of the individuals who participated in the focus groups, the organizations listed above who hosted or co-sponsored focus groups, and the individuals who served as volunteer facilitators and note-takers.

Adults Focus Group: Project ACTION!
September 9, 2007

Facilitated by Mary Lou Meccariello, Executive Director, The Arc of the District of Columbia, with Rebecca Salon, Advisor to Project ACTION!

1. If you could change 3 things about the services you get from DDA, what would you change?
 - How do DC agencies work together through transitions?
 - Services are not coordinated
 - More convenient transportation
 - More support to manage money
 - More services for independent living, jobs, things people want
 - More options
 - Growing services

2. How would you like to learn about services that DDA has that that may support you?
 - People to let you know what services and events are available
 - Understanding how funding works
 - Understanding how to get your own home
 - Responsiveness from DDA
 - Good communication, especially on changes, funding etc.
 - Not tolerating disrespect
 - Working with the schedule of people in services

 - More responsive health care
 - Choices
 - Respect for personal space
 - Are we using best practices that are used / successful elsewhere?

3. How do you want your needs determined?
 - Need for pre-planning discussions
 - Setting my own goals at hearing status
 - Need to accept personal medical forms
 - People need to be able to set ground rules for their meetings, including topics that are off-limits
 - Assessments need to be positive and not just focused on deficits
 - Meetings need to be directed by the person
 - Assessments need to only happen if the person needs and wants it
 - Making sure health and other services continue after age 22
 - People need to know their rights
 - Treating important health and dental issues as urgent
 - Individual plan needs to reflect what you want and should be changed if it's inaccurate

- DC agencies need to collaborate on funding and services
 - Need to be formal agreements between DC agencies so that children and adults don't fall through the cracks
4. What rights are most important to you? What helps you to take action to use your rights? How do you like problems to be worked out? What is needed for you to be able to talk about a problem?
- People need to know their rights
 - Advocacy support needs to be there
 - People need to not feel vulnerable when they complain
 - Need lots of pre-planning and to hear from people first
 - People in DDA should be getting regular feedback from service users
 - Training for case managers
 - Meetings with DDA to discuss the top 3 things self-advocates want to change
5. Should the court have a say in the services people get from DDA? If so, how?
- The court shouldn't be able to force people to take medication or have things in their goal plan
 - The court may have a role for some people

**Adults, Youth and Direct Support Professionals Focus Group
September 29, 2007**

Facilitated by Tony Records, TRA Consultants, Inc.

1. If you could change 3 things about the services you get from DDA, what would you change?
- ISP plan and planning process – the law should ensure that individuals should always express what they want and demonstrate through supports what they want.
 - People should live where they want to live and describe what kind of place they want to live in
 - People should have a right to choose their medical doctors and other clinical specialists
 - People should have the right to a second opinion
 - People should be trained on how to plan for their meetings, lead their meetings and advocate for their rights and needs
 - Law should allow for adequate transportation to and from activities and anywhere people want to go
 - People should have a job they choose / prefer and located where they want it to be. Should have option to do different jobs / what they want to do

- Law should include opportunity for full range of community activities, greater independent living options
- People choose their own staff to work with them
- People have sufficient amount of food for an individual to be able to spend on personal items
- People should have the right to refuse services / supports if people don't want them
- Realistic case management load so case managers can spend face to face time with individuals. Call them "support coordinators"
- People should be able to choose their own case manager
- Case managers should be highly qualified
- People should be able to change case managers
- Educate individuals on how to choose and change case managers
- Keep good relationship going
- People need full understanding and disclosure of individual's money, bank statement and accurate information
- Conservators / guardians / lawyers should meet with you on a regular basis and inform you on things you need to know
- People should determine if you really need a lawyer, or if you are someone who needs an advocate. Rights should be protected and heard.
- Driver education / travel training should be included in people's supports
- People who work should have the same rights and benefits as all people (e.g., pay, overtime etc.) – real pay, working and getting full money
- System of pay for medical services up front / or reimbursement for people quickly and adequately if consumer pays up front

- Microboards, coops – Yes! A great idea.
 - Tony Records: To do this requires strong money management, bookkeeping and full disclosure / transparency
- Microenterprise – also a good idea
- To do both microboards and microenterprise requires training and supports
- What happens if DC doesn't pay a bill (and there is a microboard)?
 - Tony Records: There is a need for a complaint system
- If I had a microboard, would I need a case manager?
 - Tony Records: Yes, at some level. Could also be a support coordinator

- Need a Support Coordinator, not a case manager, under the waiver
- Services aren't reaching the person; the case manager is not getting the job done so we need a Support Coordinator
- Get this kind of feedback / meeting with case manager [CMS?]

2. Should DDA expand its services and if so, how?

- Law should allow for continuity with recreation
- Law should help everybody with a physical or mental disability – it should be broad – look at the ADA

- The law currently services adults but in the future should also serve kids.
3. Should DDA change the individual service planning process and if so, how?
- [If I had a microboard, would the ISP be different?
 - Tony Records: No, everybody needs a plan.]
 - Yes, the ISP process should be changed:
 - The people who attend should be who you want
 - There should be a way to preserve confidentiality –
 - You should be able to choose who's at what part of the meeting (for example, I may want my employer to be at some but not all of the meeting)
 - Health information and information you want kept confidential should be
4. How do you like problems to be worked out? What is needed for you to be able to talk about a problem?
- There should be a phone number – with a live person – to phone in complaints, along with some assurance of a timely response
 - Advocates / staff should be available to help ensure follow up on complaints
 - People should be told how long it will take to get a response
 - There should be a higher level of appeal
 - There should be a standard for a quicker-than-usual response for health/safety complaints – keeping in mind that the definition of what constitutes a health/safety emergency is individual – an emergency for one person may not be an emergency for another person
 - Fire insurance, adequate insurance
 - Who manages the complaint system? How do we ensure oversight of the complaint process?
 - There should be an annual report on complaints
 - There should be an annual survey
 - Providers of in-home supports should be clear that they are working at the client's direction and schedule
 - Respect and choice
 - Respect should be a requirement
 - You should be able to choose someone else if you don't like your in home support provider
 - There should be a requirement for providers (including agencies as well as health and other allied providers) to train staff on respect, which should involve people with disabilities as trainers
 - The law should have a built-in mechanism for an annual review of the law's implementation by the DC Council
 - Allegations of neglect/abuse should be thoroughly investigated. The results of the investigation should be shared with the consumer. There should be an annual report on these investigations to the DC Council.

- Also: who to call when the law is broken? There should be some sort of oversight process for the law.
- Investigations: Police may be called, but there is not always a police report; staff may be let go, but can they be hired by another provider
 - There should be a thorough investigation
 - When a criminal act occurs, it should be prosecuted
 - Need to collect data on investigations
- Can DDA set up a database or registry of staff who commit abuse / neglect?
 - Tony Records: Some states have this, but it often has limited utility and can be difficult to administer.
- Pending investigations, there is a need to put protections in place to prevent a recurrence
- DDA needs to have procedures to hear and document concerns
- A complaint system needs to be able to include people who communicate nonverbally
- Need to ensure access to attorneys
- DDA needs to have a cooperative agreement for training, collaborative work and information sharing with “first responders” such as Metropolitan Police Department, Fire and Emergency Medical Services
- Qualifications for group home owners and direct support professionals –
 - Review of licensing and regulations?
- Incident reporting
 - There should be follow up with the individual
 - What are the consequence of an incident?
- Need for a comprehensive, quality incident review process that includes corrective actions and sanctions.
- Services including employment services must be timely and demonstrate results (e.g., getting a job)
- DC government should hire people with disabilities
- Residential / day / job should work together and shouldn’t be “either/or” – need to be flexible
- Need supported living
- With employment, there should be no discrimination base don other disabilities e.g., if someone has seizures, they should not be removed from their job
- Involvement of Mayor – there is a need for the Mayor to fully support interagency meetings, coordination etc.
- Need a picnic! To have fun – need more opportunities for recreation.

**Advocates Focus Group: Quality Trust for Individuals with Disabilities
October 23, 2007**

Facilitated by T.J. Sutcliffe, Director of Advocacy and Public Policy, The Arc of the District of Columbia

1. How could DDA better help people to learn about DDA services?
 - Provide more information in high school geared toward transition

- Make better use of the DDS web site for marketability – include brochures about services, menus, forms for applying etc. on the web site
- Use cable TV (and other media) to publicize services
- Partner with Answers, Please!, Social Security to do outreach
- In general, ensure that other service providers – like hospitals etc. – have information they can share with families about DDA services and how to get services

2. How can DDA best learn about the needs of the people it serves?

- Quality assessments should:
 - Happen in the most natural environment e.g. home, neighborhood
 - Be functional
 - Be person-centered
 - Be done by people who are familiar with the individual whenever possible
 - Be based on standards and have built-in quality control
- Need more work-based skills assessment to happen
 - Need to improve the tools for this
 - Need to improve the interpretation and application of assessments

* All services, and especially assessments and eligibility determinations, should be delivered in a timely manner within a defined time period. People should have a way to get information on the status of their assessments and eligibility determinations.

3. Are there services for individuals that DDA should offer, that it doesn't offer now?

- Orientation (should it be mandatory?)
- In-home supports
- Personal care aide and other “low level” services in the home
- Need to reverse the institutional / group home bias
- Services for people with developmental disabilities who have kids:
 - Child custody
 - Parenting training
 - Sex education
 - Etc.
- Meaningful environmental adaptations [the program exists but is not meaningful / people aren't getting the adaptations they need]
- Educational options
- Crisis intervention
- An array of meaningful day options

4. Are there services for families that DDA should offer, that it doesn't offer now?

- Respite
- Family training
- In-home supports

- Family-to-family supports

* For all services (for families and individuals) – there needs to be an improvement in responsiveness and different services need to be offered.

* All services should be quality and meaningful, and there should be methods of measurement / evaluation, potentially with a “stick” built in for poor services.

5. Should DDA expand the scope of its services to serve additional populations, and if so, how / to whom?

- DDA should also serve:
 - Parents with developmental disabilities and their kids
 - Individuals with co-occurring developmental disability and mental illness
 - Individuals who have an I.Q. above 70
- Theory vs. reality – it’s scary [to think of DDA taking on more]. But the answer has to be “yes” because people need the services.
- The “Big Answer”:
 - Developmental Disabilities: Yes – in 3 to 5 years
 - * Definitely should include autism to begin
 - * Will need to build assessments and data collection into the process, to be able to plan for both short term and long-term expansions. Data can come from DDA but also from other agencies e.g., forecast with the schools.
 - Disabilities (regardless of whether developmental): Yes -- over the longer term

Phase In
Need to be Realistic

6. What rights are most important to DDA consumers?

- Knowing them
- Asking them
- Respecting them
- Choice (for example, to change case managers; how does this interface with administrative billing versus the waiver?)
- Circle of support
 - Having knowledge regarding
 - Leading, convening ISP meetings etc.
- Consumers should be able to get rid of their attorney [if they don’t like the attorney etc.]
- Self-determination
- Right to choose your representative payee [shouldn’t be DDA]

7. Should the court have a say in the services people get from DDA? If so, how?

- People should be presumed competent to make decisions

- Are courts knowledgeable about disability, DDA's capacity etc.?
 - Court involvement -- trade off with rights
 - If we remove the court:
 - need to put other safeguards in place e.g., person-centered planning etc.
 - Need to have a transition plan
 - Court not considering the individual
 - Whether someone is committed or admitted shouldn't affect the services they receive
 - If we remove commitment, is no one due an attorney? How do we guarantee due process and remedies?
 - Families – may be hard to educate [about why removing the court might be good; families who have worked with this system for many years may not be comfortable with change]
 - What about people with no family who are committed?
 - How to preserve access to adequate legal representation, if we remove the court?
 - The court is superseding personal choice
 - Need to emphasize non-legal advocacy, and access to non-legal advocacy
8. How do consumers like to have problems resolved? What would help consumers to be able to talk about a problem?
- Need a grievance process – Yes!!
 - A grievance system must be:
 - Independent
 - Legitimate
 - Quality
 - Include education for people to know how to use the grievance system and when to call in the court
 - Don't have to have an attorney
9. If you could change 3 things about the services DDA provides, what would you change?
- How they manage people's finances
 - Responsiveness, timeliness
 - Case managers should be accountable to the people they serve. This is the linchpin!
 - Intake – everything about it, A to Z
 - Standardized system for staff training
 - Decent Human Resources department that can help DDA separate the “wheat from the chaff” through progressive discipline
 - Focus the system on personal choice versus provider choice
 - Track turn-away data from providers; providers shouldn't be able to refuse people who are eligible for their services
 - Family involvement

Families Focus Group

October 6, 2007

Facilitated by Mary Lou Meccariello, Executive Director, The Arc of the District of Columbia, and T.J. Sutcliffe, Director of Advocacy and Public Policy, The Arc of the District of Columbia.

1. If you could change 3 things about the services your family member or you get from DDA, what would you change?
 - Starts with transition / IEPs
 - Schools need to be involved and communicate with families
 - DDA should partner with schools
 - Families must be supported
 - Service coordination / service planning needs to be improved
 - Children younger than 16 need transition planning and support
 - Out-of-state schools need to be education
 - Need to educate families on services, supports and laws
 - How do parents cope, what do they do to get help. Medical profession knows diagnosis and needs to inform families what schools are best
 - Medical / doctors / attorneys / schools / other professionals need to develop (better) partnerships with families; DDA and schools should work together on this
 - Advocacy training needed for families
 - Lifespan supports / plans for families
 - Advocacy / supports for families after individual leaves the schools

2. How do you want the needs of your family member, and your needs, determined?
 - Schools need to make formal referral to DDA, the earlier the better, prior to age 16
 - EPSDT through Medicaid: what role could DDA play? Go through hospitals, doctors to get information
 - City-wide management information system from birth that tracks where people are
 - Who should lead agency be to help families plan for services?
 - DDS!
 - Get involved at a younger age (with service planning)
 - Parents have no knowledge of what DDS offers.
 - Not serving families with kids
 - Need early alert system

3. What would help families better support their members with disabilities?
 - Need in-home supports, respite, family support fund like other states
 - Strong education and training for families to understand disability services, best practices
 - Establish special fund for families
 - Medicaid, Medicare, Social Security – need benefits education for families before the child is 16

4. Should DDA expand the scope of its services to serve additional populations, and if so, how / to whom?
 - Coordination of services for children, youth, families
 - Early Intervention / DDS coordination
 - Partners in policy making advocacy training from age 1 to 21
 - Parent center being planned in each Ward (by schools). DDA should look at new legislation on this / partnerships
 - DDS needs to be very flexible to fill gaps and serve multiple systems that exist
 - Coordinate with mental health
 - Young parents under age 21 – currently there is a gap; DDS needs to plan for these individuals as it relates to current laws
 - Need for culturally sensitive providers to work with families and individuals
 - Advocates in community need to be assigned to families

4. Should DDA serve other disabilities?
 - DDA should fill gaps in autism, traumatic brain injury,
 - Adaptive skills and other developmental disabilities that affect general life skills (provide supports)
 - Eligibility for SSI and other benefits at age 22
 - Addressing before and after school care for children with disabilities (gaps)

5. What rights are most important to you? What helps you to take action to use your rights?
 - Availability of assessment information
 - Childcare and recreation
 - Gaps in medical files / services
 - Financial supports
 - Family-driven services, equity of services to all families

6. How do you like problems to be worked out? What is needed for you to be able to talk about a problem?
 - Need a clearer process for grievances that is culturally sensitive
 - Understanding intent of all laws, rights to due process and mediation
 - Process of who to talk to when there is a need and (getting) the response in a realistic timeframe and effectively
 - DDA process should be comprehensive, appropriate, and facilitate communication through the system, courts and community
 - Need for a support person in after school care that ensures health and safety
 - Certified day care legislation to protect children with disabilities
 - System of family centered groups / family advocates

7. Should the court have a say in the services people get from DDA? If so, how?

- DDA should increase its scope of responsibility at a very early age
- Increase guardianship opportunities, as opposed to court commitment
- Courts need to help families with systems problems, needs i.e., transportation
- Current guardianship laws need to work better and improve quality of life, independence and choice, i.e. health care decision making model for limited and short term guardianship
- In many ways, the courts have been filling the gap caused by the lack of a meaningful grievance / problem resolution system at DDA. If DDA implements a good grievance system, this may allow for a different role for the court.

**Families Focus Group: HSC Pediatric Center, P.A.L.S. Group
September 9, 2007**

Facilitated by Mary Lou Meccariello, Executive Director, The Arc of the District of Columbia, and T.J. Sutcliffe, Director of Advocacy and Public Policy, The Arc of the District of Columbia.

1. If you could change 3 things about the services your family member or you get from DDA, what would you change?

Note: Only a few families in this group have members who are currently receiving DDA services.

- Faster response
 - Better communication
 - Respect, use of respectful language
2. What would help families better support their members with disabilities?
 - The money should follow the individual / family (not the providers)
 - Choice
 - Respite
 - In-home companion services
 - More flexible services and more self-direction of services
 - Better / more help with service planning
 - DDA should be able to generate creative, new models – piloting programs, modeling best practices
 3. How would you like to learn about services that DDS has that that may support your family member with a disability and you?
 - Should be able to get more information from / at the schools
 - Have DDA at the table (in the schools, at IEP meetings etc.) from day 1. The IEP is an education plan, not a service plan. DDA should help families out with service planning. This can't start too early.
 - Internet

- DDA should work more with community groups – like the HSC Pediatric Center care managers – to make sure they have information about DDA services
4. How do you want the needs of your family member, and your needs, determined?
- There should be a profile of the person’s disability that is individualized and person-centered (unlike current profiles which often are not)
 - Assess the individual’s skills and strengths
 - The profile should be a living document that changes as the person’s needs, abilities and interests change
 - There should be a plan to periodically revisit and reassess labels/diagnoses
 - Appropriate clinical expertise on assessments is needed
 - The assessment / label / diagnosis should relate directly to the supports / services that are needed
 - A behavior plan should be included and kept up-to-date, where needed
 - It would be helpful to be able to share the profile between various specialists so that the individual does not have to be constantly reassessed. However, the group recognized that this could create tradeoffs / issues with confidentiality and thought this might be an area for further study.
5. Should DDA expand the scope of its services to serve additional populations, and if so, how / to whom?

NOTE: The group did not reach consensus on this topic. One parent whose child has a diagnosis that may not qualify for DDA services initially expressed an interest in seeing DDA services expanded. However, she was not familiar with services currently offered. In general, however, the group put forward the following proposal:

- DDA should continue to serve people with a primary diagnosis of MR. The group expressed concern that DDA’s current services are poor, and worried that the agency is not in a position to expand its services to people with other developmental disabilities / other disabilities.
 - However DDA can better serve people by servicing younger individuals and by providing enhanced family supports, including supports for families of younger individuals (see above). In particular, the group felt that DDA could do more on:
 - Youth-to-adult transition
 - Support for services, DCPS curricula to prepare youth for work/life
 - Behavioral supports, planning and treatment
 - Family supports (especially respite and in-home supports)
 - DDS might look at establishing a 3rd administration to work with individuals with other disabilities.
6. What rights are most important to you? What helps you to take action to use your rights?
- Ready access to accurate information
 - Proficient services

- Basic civil rights – we have laws, let’s enforce them!
 - Respect
 - Equal access (not, “most appropriate” access)
7. How do you like problems to be worked out? What is needed for you to be able to talk about a problem?
- Training
 - Having a clear process and knowing how to access that process
 - Having access to legal protections and legal services (free / sliding scale)
 - Having the option of arbitration or an ombudsman
 - Being able to meet directly and promptly with government officials (not getting the run-around and having to wait months)
8. Should the court have a say in the services people get from DDA? If so, how?

In general, the group felt that there may be a role for courts but had concerns about the scope – going to court is not for everyone – and the potential intrusion into people’s and families’ lives:

- Scary / big brother
- Going to court should be individual-based
- Can there be criteria to say if an individual should have to be involved with the court?
- What safeguards can be put in place?

**Service Providers Focus Group: DC Coalition for Community Services
October 9, 2007**

Facilitated by T.J. Sutcliffe, Director of Advocacy and Public Policy, The Arc of the District of Columbia.

1. Are there services for individuals that DDA should offer, that it doesn’t offer now?
- More services for children of families where there are parents with disabilities. What about the kids? These families need:
 - Transportation
 - Parenting classes
 - Planning
 - Daycare, summer services
 - Services and supports for people who have autism
 - DDA should have a provider relations / technical assistance office to providing support with billing, help for new providers etc.
 - A system of care for diagnoses
 - Stronger short-term stabilization for people with a dual diagnosis of developmental disability and mental illness
 - Transition supports for people with short-term medical problems
 - Services for people with developmental disabilities who also have a substance abuse disorder / alcoholism

- A shorter timeframe for people to work through RSA to get supported employment services at DDS
2. Should DDA expand the scope of its services to serve additional populations, and if so, how / to whom?
- For any expansions, money / resources must be adequate
 - DDA should definitely expand to serve children and their families
 - DDA should also expand to serve people with autism
 - Beyond that:
 - Should DDA serve people with all developmental disabilities – (Small question mark)
 - Should DDA serve people with all disabilities, not just DD – (Large question mark)
3. Should the court have a say in the services people get from DDA? If so, how?
- Perhaps through the guardianship process
 - Definitely: Nix the annual hearing process
 - Need to examine the usefulness of commitment
4. If you could change 3 things to help you provide services better, what would you change?
- More available, skilled and willing case managers (in adequate numbers, with appropriate case loads)
 - DDA should have a provider relations resource coordination to assist both new and existing providers
 - Health and fire standards need to be
 - All on the same page
 - Individualized and reflected in the ISP (e.g., what are the individual's sensitivities to various chemicals, risks related to hot water, etc.)
 - DOH currently contracts with FEMS; DOH should contract with DDS to do QA
 - Coordination with relevant associations and boards e.g. American Psychological Association, DC Hospital Association, Nursing Board etc.
 - Healthcare – there needs to be a vision beyond the current narrow view which instead integrates people with developmental disabilities into the broader health care system to ensure access

* In general, how do we make these issues, especially of interagency coordination etc., not just DDA's responsibility but the whole city's?

Youth Focus Group: Advocates for Justice and Education, Inc.
Friday, October 26, 2007

Facilitated by T.J. Sutcliffe, Director of Advocacy and Public Policy, The Arc of the District of Columbia

1. Name concerns that you have as you graduate or exit from school. What do you need to succeed?
 - Stay out of trouble
 - Be able to go to college
 - Get assistance and information on scholarship money
 - Diploma
 - Tutoring
 - Community service opportunities
 - Hands-on training classes
 - College prep classes
 - RSA
 - Mentoring
 - College fair
 - Getting information and resources as early as possible to start preparing to graduate
 - Teachers / counselors who are there for you and who are knowledgeable about who the “go to” person is (for services I need)

2. How do you like problems to be worked out? What is needed for you to be able to talk about a problem?
 - Being able to talk to someone
 - Schools should make sure things are working
 - Having someone to help solve problems
 - Involving parents and students in solving problems

3. What rights are most important to you? What helps you to take action to use your rights?
 - Having someone to show the way, to show how (to use my rights)
 - To be taken seriously
 - To be treated in a respectful manner
 - (To receive services that are) timely
 - Personal space
 - To not be singled out
 - To get clear and detailed information

 - Additional comments on rights, from parents:
 - What is too much (expectations)?
 - There needs to be a one-on-one focus, a focus on the family team, and a backup of advocacy supports

**Youth Focus Group: National Children's Center Youth Empowerment Group
October 17, 2007**

Facilitated by Laura E. White, Project Manager, Inclusion Research Institute Youth Empowerment Resource Center

1. Name concerns that you have as you graduate or exit from school. What do you need to be successful?
 - Diploma
 - Good job
 - Good grades
 - Good behavior
 - Good listening skills

2. How would you like to find out about services and supports that are available to you?
 - Social workers
 - Supervisors
 - Peers
 - Attending events such as a job or college fairs

3. What would help you to work better with staff?
 - Respect
 - Training on how to get along with staff and peers (Human Relationships)
 - Training on understanding intercultural relations (staff come from other countries and young people need to understand cultural differences)

4. What are some actions you can take if you have a problem?
 - Excuse yourself or leave the situation
 - Take a walk
 - Break things
 - Talk to someone about the situation

5. What rights are most important to you?
 - Right to go to classes (college)
 - Right to three meals a day
 - Right to go to the bathroom
 - Right to personal space
 - Right to walk around
 - Right to speak
 - Right to ignore people
 - Right to be respected

NOTE: RIGHTS TO RESPECT AND PRIVACY ARE THE MOST IMPORTANT.

6. How do you feel about your yearly Individual Support Plan Meetings?

- They are ok.
- I do not like to answer questions in front of a bunch of people, and I want to give answers to one or two people before the meeting.
- They make me talk about things I don't like.

7. How do you feel about going to court?

- Sometimes it is pleasant, but it can be very stressful
- I go to court a lot (once every 2 to 3 months; staff confirmed this information)
- If I disagree with a court decision, it is very stressful, and I want to runaway.

8. Are there any services or supports that you need that you do not have right now?

- Independent living services
- Own transportation so that I can come and go on my own. I would prefer a car and Driver's License, but I would settle for a bicycle.
- Reunification with family
- More visits with family especially at the holidays
- Pet dog
- Space camp