“From your perspective, what are the key resources needed by parents, child care providers, health care providers, educators, and community groups and service providers to effectively identify, serve and support children and youth with ASD and other developmental disabilities?”

**Parents/Family**

*(early childhood)*
- Parent to parent interaction, school, church, friends. Differing stories of HOPE
- Internet searches: symptoms, DX
- Local autism group
- Autism Tx Provider: IDS, Common threads, WEAP
- B-3/ECE
- County programs
- Ways to pay
- Developmental Pediatrician
- Day care

*(school age)*
- Parent to parent sharing of info re: camps, resources, IEP, accommodation, etc.
- Autism training for school staff ongoing
- Resource Directories
- Conferences with childcare
- Access to supported recreational activities
- Appropriate supports to address family and marriage stress
- Peer education
- Parent leadership/trainings
- Sexuality and peer issues
- Legal issues

*(transition to adulthood)*
- Person- centered planning (PATH)
- Info about post secondary education- tech college
- Legal issues P.Q.A.
- IEP-transition resources
- DVR LOV-Dane
- Financial issues, guardianship, SSI
- Parent to Parent
- Community service teams (CST) (wraparound)
- Work and play
- Rules of life/safety
- Housing

*(The bottom line)*
- Treat whole family
- Know where resources are
- Helping families connect with other families
- Internet community and resources
- Trust your instincts
- Bottom line: respect
- Basic skill development that is the foundation for life
- Positive behavioral supports

**Community**

1)  
- Funding
- Programs (not just DD)
- Transition/Adulthood
- Someone to help sort things out
- Kids accepted for who they are
- Parents dealt with honestly- no cure
- Parents learn about evidence based Tx
- Stress communication disorder
- Legal rights
- You are not alone

Wish List:
- single point of entry (one point of entry that branches between 0-18 and >18)
- Availability of programs/funding
- Legal transition
- Honest and beneficial advice
- Child first
- Not just looking for a cure attitude
- Positive attitude
- Like ARDC for children/inclusive

2)  
- word of mouth
- list serves
- shared "secret" lists

**Education**

- Get them to the Diagnosticians:
  - Southern Resource ctr.
  - First Step

*To supply them with someone to give a diagnosis
- WSPEI- parent liaisons
  - Special ed. Director- district (chairs)
  - DPI trainings
  - CESA trainings
  - Good friends, INC – services
  - Autism internet modules-national professional center
  - PBS and CPS training
  - CESA- not all should have a contract
  - School social worker and special education
  - Diagnosis local autism chapter (Waisman Center, Regional center, First step)
  - Educator resources (Waisman, First Step, Regional center, School social worker/psychologist, staff as resource)
  - Diagnostician: Southern Regional center, First Step, PINT clinic
  - WSPEI parent liaison
  - OCALI
- Because parent info is so powerful, increase parents as leaders training and training for parent liaison at all resource centers on evidence based practices. Also provide training on how to be positive and affirming of parent tx choices while also providing accurate info about evidence for the treatments.

**Child Care Providers**

What do you wish your childcare provider had known?

1. Where to go to find resources
   a. How to refer and check into concerns, where to send people when there are concerns
   b. Community resources: MA assistance, case management, advocacy. Financial support. Respite
   c. Medical and assessment: Early diagnosis
   d. Communication. Behavioral supports. Education

2. What resources does the child care provider need?

- How to effectively support needs of child with positive behavioral supports/FBA
- Inclusion supports and extra money help, UCP
- Behavior is communication
- Knowing how to do it different
- Support specialists to regularly consult and discuss with (EBP) child care providers/teachers
- Third party payers need to allow adequate collaboration and support for daycare providers (e.g. autism tx provider sable to do therapy at daycare)

**Health Care Providers**

What parents think Health care providers should have:

1. HC providers need to respect parents concern and take timely and appropriate action
2. HC providers need resource lists:
   a. resources list for parents (1-pager)
   b. Resource list for themselves for referrals
3. HC providers need to continue to think and learn about possible co-morbid conditions (medical or disability) that may be masked by the initial diagnosis.
4. need to be aware of medications:
   a. availability
   b. appropriate meds for ASD
5. Require all HC providers to go through ASD 101 training....include ASD in medical school curriculum

What healthcare providers think they should have:

1. First steps for doctors that covers life-span.
2. A 1-page resource list to go to families (in multiple language and in DVD format as well)
3. ASD-medical website including: basic info, videos, screener
4. Basic ASD in as part of medical school training and continuing education

- There was considerable discussion about parents educating doctors- unfortunately too many doctors will prescribe too whatever the parent suggests and therefore ‘legitimizes’ the treatment.
- Understand alternative therapies
- DAN??