

2014 MD Parent Survey Results

ASD/DD and E/SD Subsample
Highlights

Purpose

- Parents of children and youth with special health care needs (CYSHCN) were surveyed fulfill the mandated Maryland Title V Maternal and Child Health Block Grant 2015 Needs Assessment as well as to help evaluate two federal grants: “State Implementation Grant for Improving Services for Maryland Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities” and “Access Improvement Grant for Maryland Children and Youth with Epilepsy.”

Methods

- Survey respondents were recruited through Parent's Place of Maryland, Maryland Center for Developmental Disabilities, local health departments, Pathfinders for Autism, Abilities network, etc., via email listservs and in-person events
- Survey was available online (via Survey Monkey) and paper and pencil

MD Parent Survey Demographics

- There were 1,090 parent respondents in the 2014 MD Parent Survey
- Male and non-Hispanic white children were overrepresented in the sample
- More than half of children were covered by private insurance only (56%).
- The counties most represented in this sample were:
 - Baltimore County (14.8%)
 - Frederick (12.6%)
 - Montgomery (10.8%)

Child Characteristics	Sample n	%
Age		
0-5	204	18.7
6-11	395	36.2
12-17	349	32.0
18+	134	12.3
Sex		
Male	748	68.6
Female	341	31.3
Race/Ethnicity		
Non-Hispanic White	720	66.1
Non-Hispanic Black	194	17.8
Non-Hispanic Asian	29	2.7
Hispanic	72	6.6
Other, non-Hispanic	72	6.6
Health insurance		
Private insurance only	580	55.7
Public insurance only (Medical Assistance/Medicaid/Military/MCHP/Medicare)	339	32.6
Private and public insurance	117	11.2
No insurance	5	0.5

**AUTISM SPECTRUM
DISORDER/DEVELOPMENTAL DELAY
SUBSAMPLE HIGHLIGHTS**

ASD/DD Subsample Characteristics

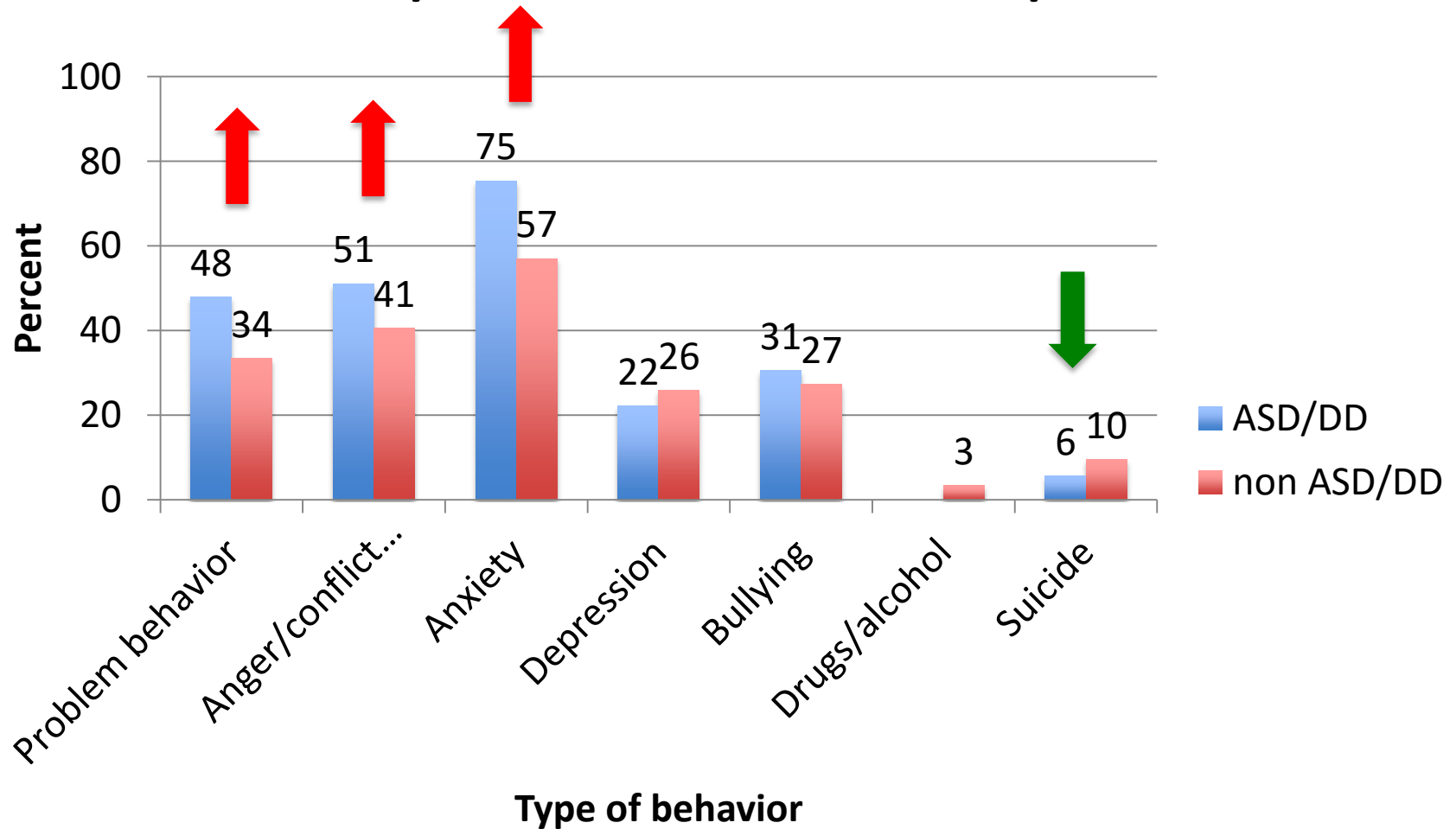
- Nearly 40% (39.2%) identified having a child with an Autism Spectrum Disorder (ASD) diagnosis (n=427)
- 8.7% reported having a child with a Developmental Delay (DD) diagnosis (n=95).
- Less than 2% of the sample reported having a child with both ASD and DD (1.7%; n=19).
- Combined, 46% of respondents to the MD Parent Survey were classified as having children with ASD/DD (n=503).

	ASD/DD Sample n	ASD/DD Sample %	Total Sample %
Age			
0-5	84	16.8	18.7
6-11	190	38.1	36.2
12-17	164	32.9	32.0
18+	61	12.2	12.3
Sex			
Male	399	79.3	68.6
Female	104	20.7	31.3
Race/Ethnicity			
Non-Hispanic White	325	64.6	66.1
Non-Hispanic Black	91	18.1	17.8
Non-Hispanic Asian	18	3.6	2.7
Hispanic	39	7.8	6.6
Other, non-Hispanic	30	6.0	6.6
Health insurance			
Private insurance only	264	53.0	55.7
Public insurance only (Medical Assistance/Medicaid/Military/MC HP/Medicare)	165	33.1	32.6
Private and public insurance	66	13.3	11.2
No insurance	<5	NR	0.5

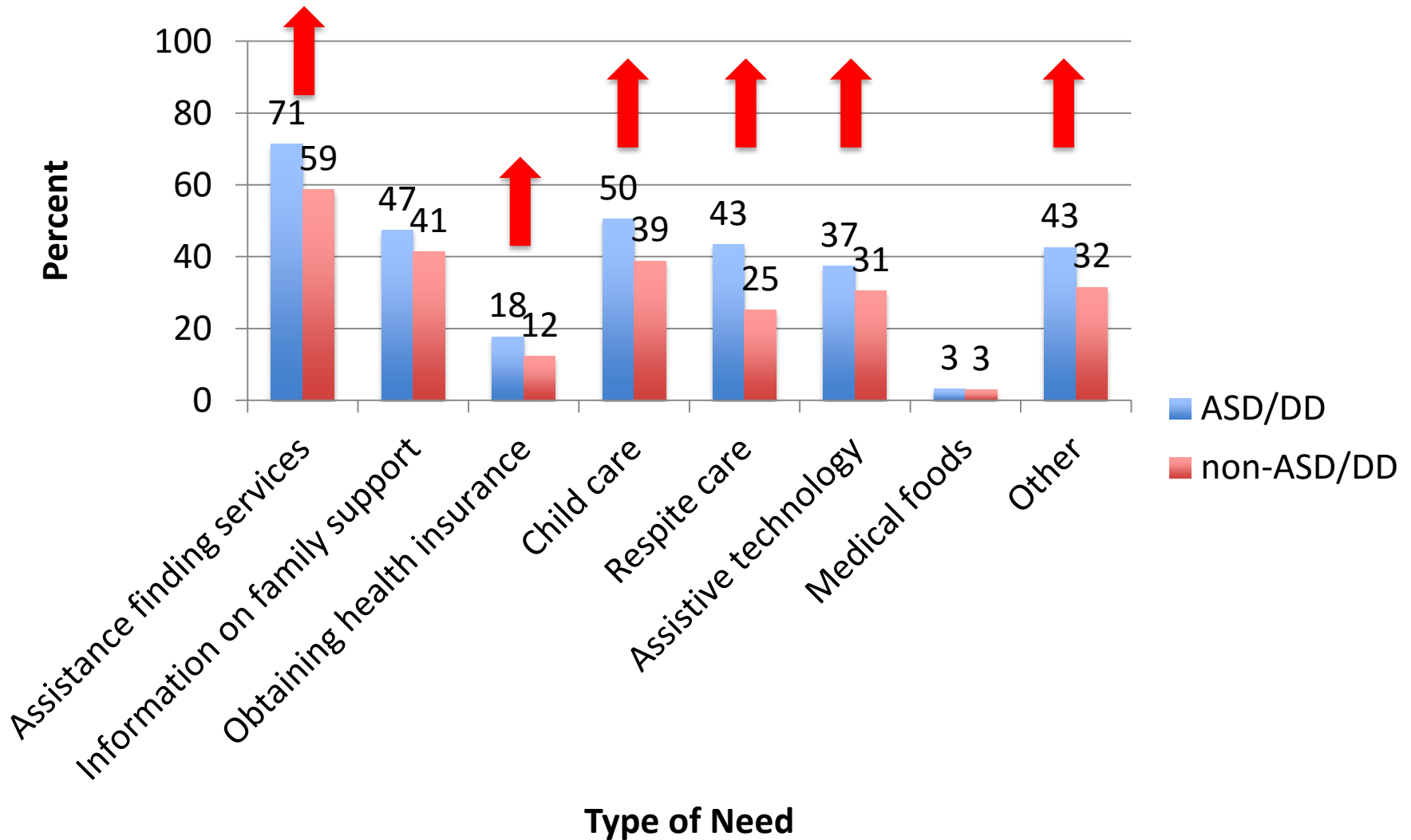
Main Findings for ASD/DD

- Among parents of children with ASD/DD compared to parents of children without ASD/DD:
 - Higher prevalence of child behaviors
 - Anxiety (75% vs. 57%)
 - Problem behaviors (48% vs. 34%, $p < 0.001$)
 - Anger/conflict management (51% vs. 41%, $p < 0.01$)
 - Lower prevalence of suicidal child behavior (6% vs. 10%, $p < 0.05$)
 - Higher prevalence of parental needs
 - Finding services for child (71% vs. 59%, $p < 0.001$)
 - Child care (50% vs. 39%, $p < 0.001$)
 - Respite care (43% vs. 25%, $p < 0.001$)
 - Assistive technology (37% vs. 25%, $p < 0.05$)
 - Obtaining health insurance (18% vs. 12%, $p < 0.05$)
 - Less shared decision making
 - Feeling like a partner in care (72% vs. 79%, $p < 0.01$)
 - Getting specific information you need (64% vs. 75%, $p < 0.001$)
 - Discussing range of options (60% vs. 70%, $p < 0.01$)
 - Overall (47% vs. 55%, $p < 0.01$)

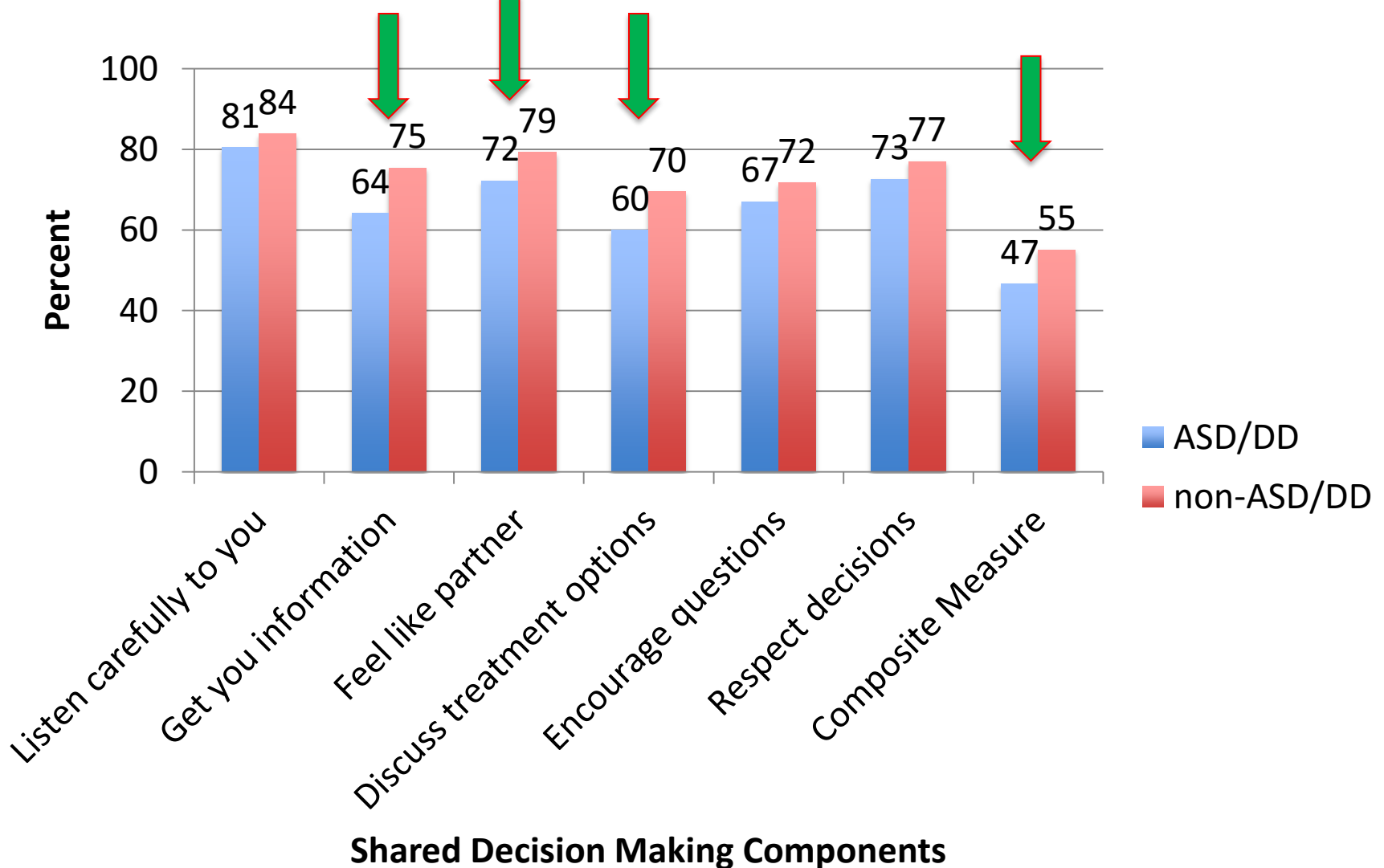
Parent-reported child behaviors (Q11): ASD/DD vs. non-ASD/DD



Parent Respondent Needs (Q15): ASD/DD vs. non-ASD/DD



Shared Decision Making (Q17): ASD/DD vs. non-ASD/DD



EPILEPSY/SEIZURE DISORDER SUBSAMPLE HIGHLIGHTS

E/SD Subsample Characteristics

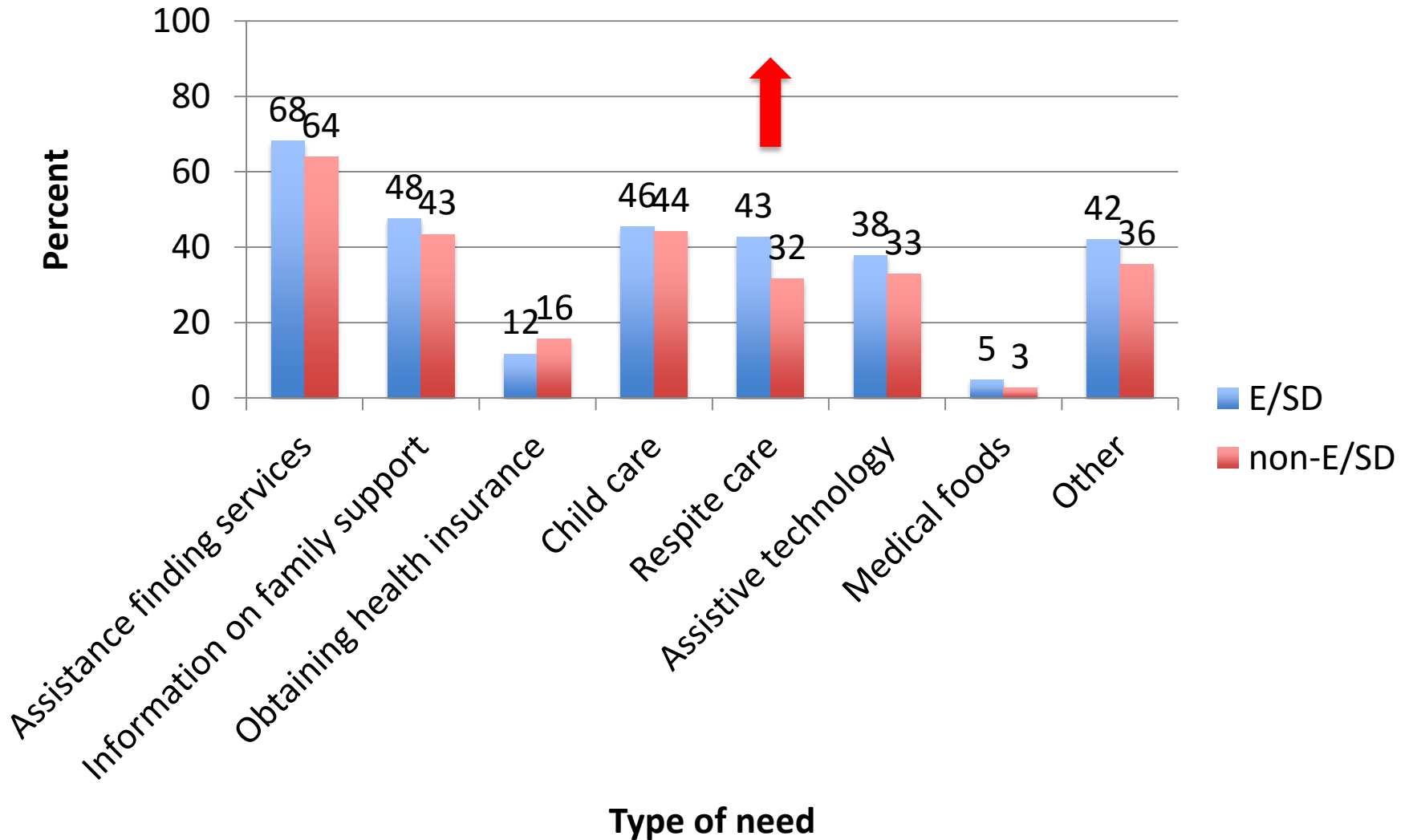
- Almost 8% (7.9%) identified having a child with an epilepsy or seizure disorder (E/SD) diagnosis in writing the child's diagnoses (n=86)
- 14.0% affirmatively responded to a screener question for an E/SD diagnosis (n=153)
- Combined, 20.6% of respondents to the MD Parent Survey were classified as having children with E/SD (n=225).

	E/SD Sample n	E/SD Sample %	Total Sample %
Age			
0-5	42	18.8	18.7
6-11	76	33.9	36.2
12-17	76	33.9	32.0
18+	30	13.4	12.3
Sex			
Male	123	54.7	68.6
Female	102	45.3	31.3
Race/Ethnicity			
Non-Hispanic White	158	64.6	66.1
Non-Hispanic Black	37	18.1	17.8
Non-Hispanic Asian	<5	NR	2.7
Hispanic	11	7.8	6.6
Other, non-Hispanic	16	6.0	6.6
Health insurance			
Private insurance only	114	50.7	55.7
Public insurance only (Medical Assistance/Medicaid/Military/MCHP/Medicare)	78	34.7	32.6
Private and public insurance	30	13.3	11.2
No insurance	<5	NR	0.5

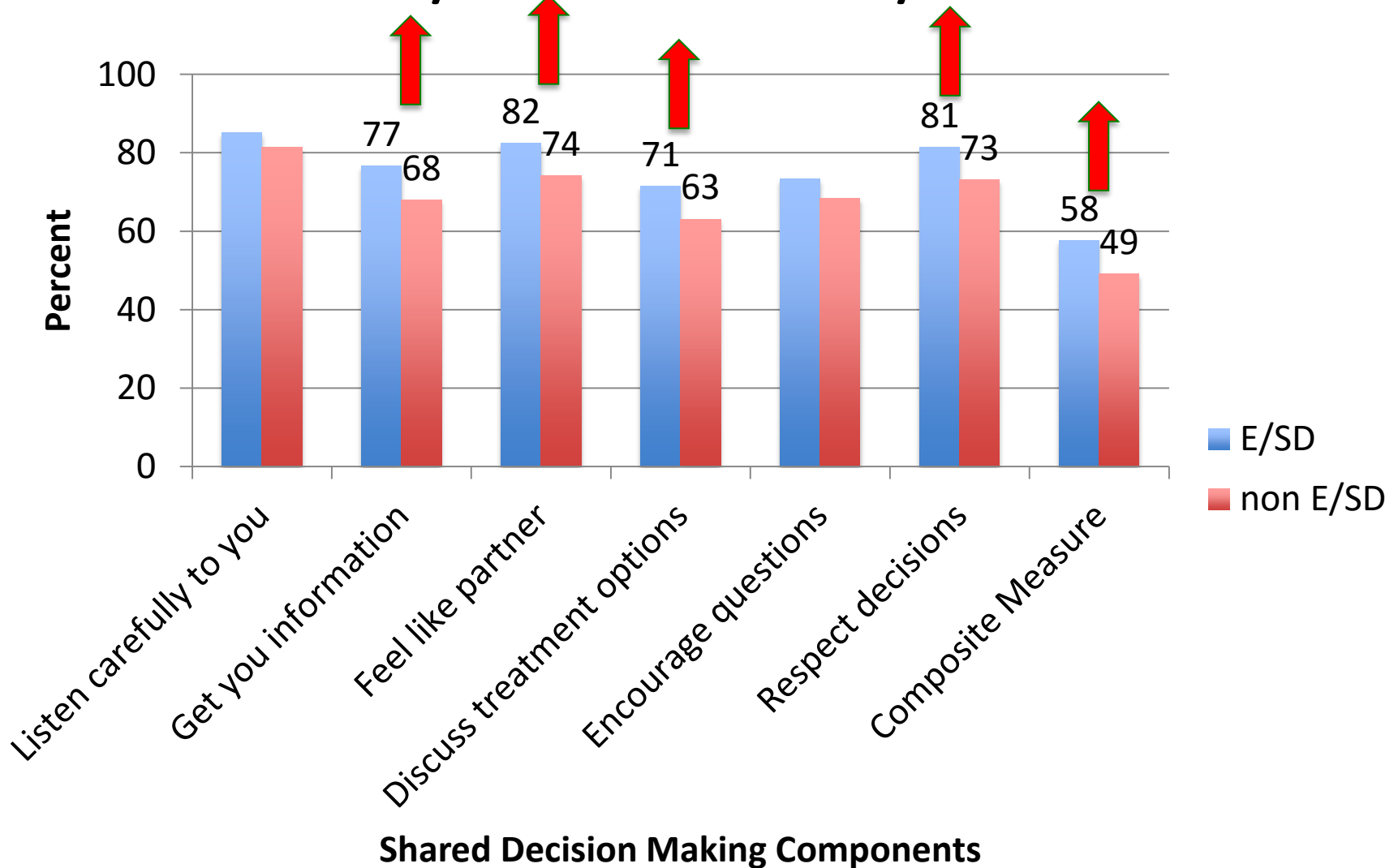
Main Findings for E/SD

- Among parents of children with E/SD compared to parents of children without E/SD:
 - Higher prevalence for needing respite care services (43% vs. 32%, $p < 0.01$)
 - More shared decision making
 - Getting specific information you need (77% vs. 68%, $p < 0.05$)
 - Feeling like a partner in care (82% vs. 74%, $p < 0.05$)
 - Discussing range of options (71% vs. 63%, $p < 0.05$)
 - Respecting decisions (81% vs. 73%, $p < 0.05$)
 - Composite shared-decision making measure (58% vs. 49%, $p < 0.05$)

Parent Respondent Needs (Q15): E/SD vs. non-E/SD



Shared Decision Making (Q17): E/SD vs. non-E/SD



Conclusions

- ASD/DD parents appear to experience:
 - More child behavior problems compared to non-ASD/DD parents
 - A higher level of needs (especially for finding services)
 - A lower sense of shared decision-making with providers
- E/SD parents, in contrast, experienced fewer child behavior problems and a much higher sense of shared decision-making with providers – but reported higher need for respite care services
 - Doesn't mean they don't experience child behavior problems or have specific service needs – just means they aren't any worse than full sample