Ontario Trillium Foundation / Fondation Trillium de l'Ontario

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Overview

The goal of the 2017 *York ASD Partnership Needs Assessment Survey* was to capture the perspectives of caregivers, self-advocates with ASD, and professionals working with children and adults with ASD and their families regarding ASD services and supports in York Region. Caregivers and professionals who completed the survey represented all areas of York Region. Majority of caregivers were parents and represented youth with ASD ages 5 to 17 years old. Majority of professionals were educators (mainly teachers) and most worked with youth ages of 5 to 17 years old. Results from the caregiver and professional surveys are presented in the report below. While attempts were made to recruit York Region self-advocates, participation remained low. Self-advocate survey results are not presented due to these low numbers; however, select self-advocate quotes have been included at the end of the report.

General Highlights

Both caregivers and professionals rated many of the listed services and supports as "extremely important". Most caregivers indicated that these much-needed services were difficult to obtain and most of these services were paid for privately. Majority of caregivers said that they could afford services but that it was a struggle, and unfortunately, a large proportion of caregivers could not afford "extremely important" services. The most frequently endorsed barrier to service access by both caregivers and professionals was waitlists. Majority of professionals also rated affordability of services as a barrier.

Participants rated their perceived overall efficiency of the system and their satisfaction with available services and supports. Nearly half of all caregivers and majority of professionals described the current York Region ASD service system as being "somewhat efficient" and indicated that there is work needed to improve its efficiency. Majority of caregivers and professionals indicated that available services were "fair" to "good" and that they were "moderately satisfied" with the services accessed, suggesting opportunities for service system improvements.

Overview of Survey Participants (*N* = 363)

2%

42%

56%

■ Adult with an ASD

■ Professional
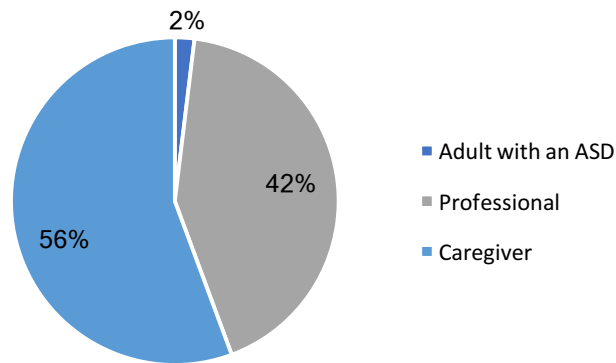
■ Caregiver

*Analyses are based on those who completed 85% or more of the survey and who indicated they lived/worked in York Region only.

CAREGIVER SURVEY RESULTS

DEMOGRAPHIC INFORMATION:
- 98% (*n* = 197) of caregivers reported that the family members they were representing had an official ASD diagnosis (2%, *n* = 4 did not have an official diagnosis).
- Approximately 79% (*n* = 159) of caregivers were representing male family members (21%, *n* = 43 were representing female family members).
- Mean age of individuals represented in survey were 12.9 years old (*SD* = 7.5; range = 2 - 54 years old)
- 78% (*n* = 158) of caregivers were mothers, 20% (*n* = 40) were fathers, and 2% (*n* = 4) included a sibling, spouse, and stepmothers.

Age Groups of Individuals with ASD Represented
(*n* = 202)

- 4 years and under
- 5-17 years
- 18-25 years
- 26-50 years & over 50 years
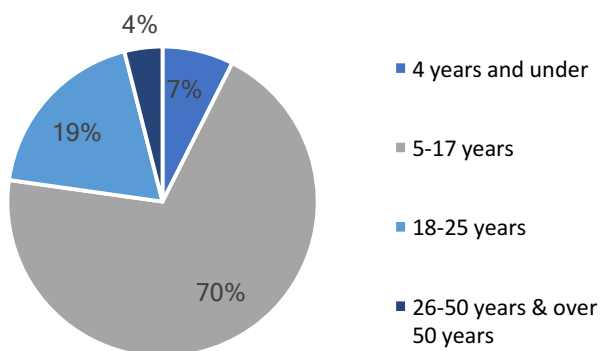
Majority of caregivers represented youth with ASD ages 5-17 years old. Young children (4 years old and under) and the older adult group (26-50 and 50+ years old) were the least represented groups.

Living Arrangements of Individuals with ASD (*n* = 202)

- At home with family
- Residential care
- Own apartment/home
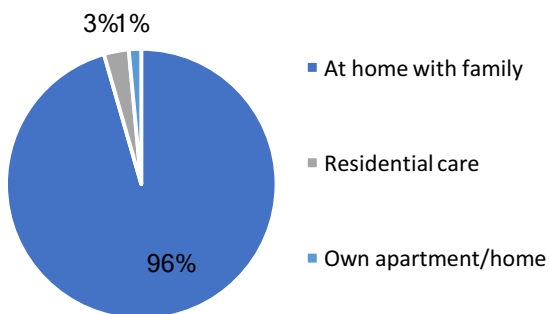
The vast majority of individuals with ASD lived at home with family.

**Percentage of Caregivers represented across York Region areas
(*n* = 202)**
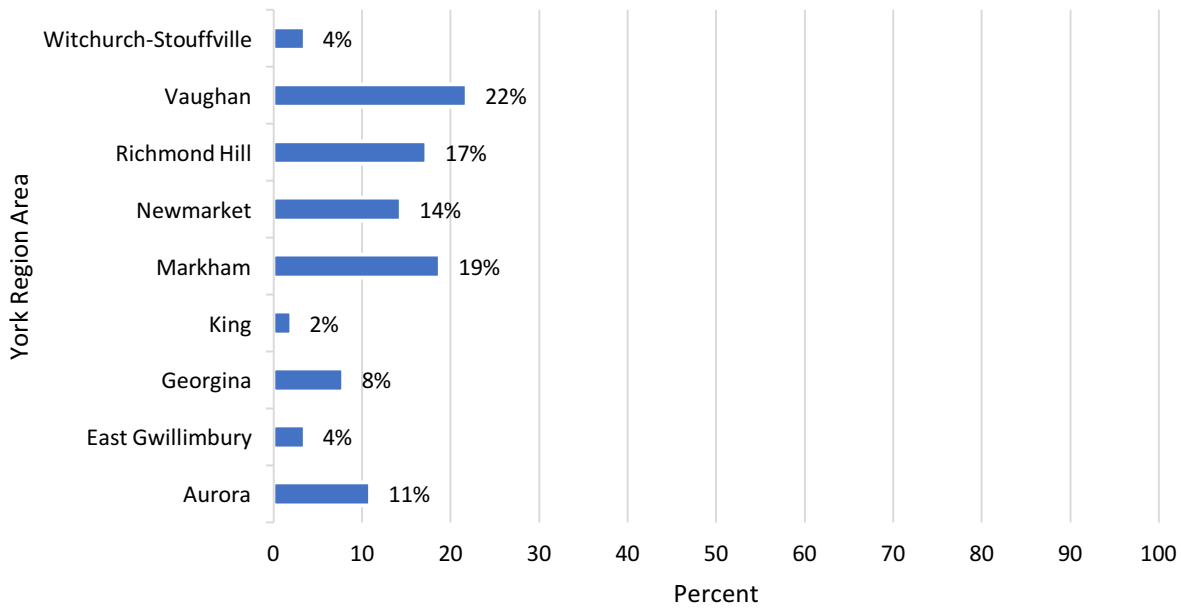
There was representation of caregiver participants across all nine areas of York Region. The more densely populated areas had relatively more representation compared to rural areas.

Importance Ratings of Various Services and Supports (4 years old and under) (N = 15) Percent (Number)					
Services and Supports	**Not at all important**	**A little important**	**Moderately important**	**Very important**	**Extremely important**
Early detection of ASD	0.0 (0)	0.0 (0)	6.7 (1)	20.0 (3)	73.3 (11)
Early ABA-based services for preschool children	0.0 (0)	0.0 (0)	0.0 (0)	20.0 (3)	80.0 (12)
Other forms of early intervention for preschool children (e.g., SLP, OT)	0.0 (0)	0.0 (0)	13.3 (2)	20.0 (3)	66.7 (10)
Daycare/preschool programs	6.7 (1)	0.0 (0)	13.3 (2)	26.7 (4)	53.3 (8)
Mainstream school supports	0.0 (0)	0.0 (0)	6.7 (1)	26.7 (4)	66.7 (10)
After-school supports	20.0 (3)	0.0 (0)	6.7 (1)	26.7 (4)	46.7 (7)
Recreational/leisure programs	0.0 (0)	6.7 (1)	13.3 (2)	26.7 (4)	53.3 (8)
Social skills/ friendship programs	0.0 (0)	0.0 (0)	0.0 (0)	40.0 (6)	60.0 (9)
Housing/residential options	33.3 (5)	6.7 (1)	13.3 (2)	26.7 (4)	20.0 (3)
Diagnostic and/or developmental/skill assessment services	0.0 (0)	0.0 (0)	6.7 (1)	33.3 (5)	60.0 (9)
Respite (in and/or out of home)	6.7 (1)	6.7 (1)	20.0 (3)	26.7 (4)	40.0 (6)
Specialized transportation	26.7 (4)	20.0 (3)	13.3 (2)	13.3 (2)	26.7 (4)
Mental health treatment	26.7 (4)	6.7 (1)	26.7 (4)	13.3 (2)	26.7 (4)
Medical services/care for adults	26.7 (4)	13.3 (2)	13.3 (2)	20.0 (3)	26.7 (4)
Crisis intervention/management	13.3 (2)	13.3 (2)	26.7 (4)	26.7 (4)	20.0 (3)
Behavioural intervention programs for behaviour management	0.0 (0)	13.3 (2)	20.0 (3)	20.0 (3)	46.7 (7)
Transition supports	0.0 (0)	6.7 (1)	6.7 (1)	26.7 (4)	60.0 (9)
Community safety training	13.3 (2)	6.7 (1)	6.7 (1)	26.7 (4)	46.7 (7)
Life skills training (e.g., money management, self-care, hygiene)	13.3 (2)	0.0 (0)	0.0 (0)	33.3 (5)	53.3 (8)
Post-secondary education programs (e.g., community college, university)	20.0 (3)	0.0 (0)	13.3 (2)	20.0 (3)	46.7 (7)
Employment or adult day programs	20.0 (3)	0.0 (0)	13.3 (2)	20.0 (3)	46.7 (7)
Parent/caregiver training programs	0.0 (0)	0.0 (0)	0.0 (0)	40.0 (6)	60.0 (9)
Family support or counselling	6.7 (1)	13.3 (2)	13.3 (2)	26.7 (4)	40.0 (6)
Additional supports for family members of individuals with ASD	26.7 (4)	13.3 (2)	13.3 (2)	33.3 (5)	13.3 (2)
Other services	66.7 (10)	0.0 (0)	6.7 (1)	6.7 (1)	20.0 (3)

NOTE: Dark yellow highlights indicate when greater than 50% of respondents indicated that a specific service or support was "Extremely Important". "OTHER SERVICES" described by respondents: IBI Treatment; financial aid.

For caregivers of children 4 years old and under, early detection and early ABA-based services for preschool children were rated as "extremely important". Services geared toward older children and adults were rated as less important.

Importance Ratings of Various Services and Supports (5-17 years old) Percent (Number)					
Services and Supports	Not at all important	A little important	Moderately important	Very important	Extremely important
Early detection of ASD	13.6 (19)	2.1 (3)	7.1 (10)	15.7 (22)	61.4 (86)
Early ABA-based services for preschool children	12.8 (18)	5.7 (8)	12.1 (17)	13.5 (19)	56.0 (79)
Other forms of early intervention for preschool children (e.g., SLP, OT)	15.0 (21)	4.3 (6)	4.3 (6)	20.0 (28)	56.4 (79)
Daycare/preschool programs	17.5 (24)	3.6 (5)	16.1 (22)	22.6 (31)	40.1 (55)
Mainstream school supports	4.3 (6)	0.7 (1)	2.1 (3)	14.9 (21)	78.0 (110)
After-school supports	10.1 (14)	7.2 (10)	15.1 (21)	25.9 (36)	41.7 (58)
Recreational/leisure programs	2.8 (4)	1.4 (2)	8.5 (12)	28.4 (40)	58.9 (83)
Social skills/ friendship programs	1.4 (2)	2.1 (3)	2.1 (3)	19.1 (27)	75.2 (106)
Housing/residential options	23.7 (33)	11.5 (16)	17.3 (24)	15.1 (21)	32.4 (45)
Diagnostic and/or developmental/skill assessment services	4.3 (6)	5.7 (8)	9.3 (13)	27.9 (39)	52.9 (74)
Respite (in and/or out of home)	8.5 (12)	6.4 (9)	14.9 (21)	24.8 (35)	45.4 (64)
Specialized transportation	26.6 (37)	9.4 (13)	22.3 (31)	20.1 (28)	21.6 (30)
Mental health treatment	7.9 (11)	7.9 (11)	17.3 (24)	22.3 (31)	44.6 (62)
Medical services/care for adults	17.3 (24)	12.9 (18)	21.6 (30)	18.7 (26)	29.5 (41)
Crisis intervention/management	15.8 (22)	7.9 (11)	21.6 (30)	21.6 (30)	33.1 (46)
Behavioural intervention programs for behaviour management	7.2 (10)	2.9 (4)	10.8 (15)	33.1 (46)	46.0 (64)
Transition supports	5.0 (7)	5.0 (7)	14.9 (21)	32.6 (46)	42.6 (60)
Community safety training	6.4 (9)	3.5 (5)	13.5 (19)	29.1 (41)	47.5 (67)
Life skills training (e.g., money management, self-care, hygiene)	6.4 (9)	4.3 (6)	5.0 (7)	23.4 (33)	61.0 (86)
Post-secondary education programs (e.g., community college, university)	11.4 (16)	4.3 (6)	12.9 (18)	15.0 (21)	56.4 (79)
Employment or adult day programs	17.9 (25)	3.6 (5)	14.3 (20)	15.0 (21)	49.3 (69)
Parent/caregiver training programs	3.6 (5)	4.3 (6)	15.0 (21)	34.3 (48)	42.9 (60)
Family support or counselling	8.6 (12)	7.9 (11)	18.0 (25)	23.0 (32)	42.4 (59)
Additional supports for family members of individuals with ASD	32.1 (45)	5.0 (7)	15.0 (21)	16.4 (23)	31.4 (44)
Other services	63.3 (88)	4.3 (6)	5.8 (8)	6.5 (9)	20.1 (28)

NOTE: Dark yellow highlights indicate when greater than 50% of respondents indicated that a specific service or support was "Extremely Important". Examples of "OTHER SERVICES" described by respondents: music & sensory classes; parent support groups; fraud & bullying prevention; EA support in schools; road map of treatments; special needs camps; ABA funding; autism acceptance support; sibling support; financial planning support.

Majority of caregivers of 5-17 year olds rated mainstream school supports and social skills/friendship programs as "extremely important". Early detection was also rated by many as "extremely important". Almost a third of caregivers rated additional family support as "not at all important".

Importance Ratings of Various Services and Supports (18 years old and over) Percent (Number)					
Services and Supports	Not at all important	A little important	Moderately important	Very important	Extremely important
Early detection of ASD	39.1 (18)	0.0 (0)	4.3 (2)	15.2 (7)	41.3 (19)
Early ABA-based services for preschool children	40.9 (18)	2.3 (1)	4.5 (2)	13.6 (6)	38.6 (17)
Other forms of early intervention for preschool children (e.g., SLP, OT)	40.9 (18)	2.3 (1)	0.0 (0)	18.2 (8)	38.6 (17)
Daycare/preschool programs	45.5 (20)	2.3 (1)	9.1 (4)	13.6 (6)	29.5 (13)
Mainstream school supports	24.4 (11)	4.4 (2)	0.0 (0)	15.6 (7)	55.6 (25)
After-school supports	31.8 (14)	6.8 (3)	6.8 (3)	27.3 (12)	27.3 (12)
Recreational/leisure programs	6.7 (3)	0.0 (0)	17.8 (8)	17.8 (8)	57.8 (26)
Social skills/ friendship programs	6.5 (3)	0.0 (0)	10.9 (5)	23.9 (11)	58.7 (27)
Housing/residential options	8.7 (4)	6.5 (3)	13.0 (6)	15.2 (7)	56.5 (26)
Diagnostic and/or developmental/skill assessment services	8.9 (4)	2.2 (1)	20.0 (9)	20.0 (9)	48.9 (22)
Respite (in and/or out of home)	27.3 (12)	15.9 (7)	2.3 (1)	18.2 (8)	36.4 (16)
Specialized transportation	25.0 (11)	15.9 (7)	6.8 (3)	25.0 (11)	27.3 (12)
Mental health treatment	6.7 (3)	2.2 (1)	8.9 (4)	24.4 (11)	57.8 (26)
Medical services/care for adults	11.4 (5)	4.5 (2)	18.2 (8)	20.5 (9)	45.5 (20)
Crisis intervention/management	8.9 (4)	17.8 (8)	15.6 (7)	15.6 (7)	42.2 (19)
Behavioural intervention programs for behaviour management	11.4 (5)	6.8 (3)	22.7 (10)	20.5 (9)	38.6 (17)
Transition supports	8.9 (4)	2.2 (1)	4.4 (2)	24.4 (11)	60.0 (27)
Community safety training	11.1 (5)	11.1 (5)	22.2 (10)	17.8 (8)	37.8 (17)
Life skills training (e.g., money management, self-care, hygiene)	2.2 (1)	4.4 (2)	17.8 (8)	13.3 (6)	62.2 (28)
Post-secondary education programs (e.g., community college, university)	17.4 (8)	2.2 (1)	13.0 (6)	21.7 (10)	45.7 (21)
Employment or adult day programs	4.4 (2)	2.2 (1)	6.7 (3)	17.8 (8)	68.9 (31)
Parent/caregiver training programs	15.6 (7)	6.7 (3)	22.2 (10)	22.2 (10)	33.3 (15)
Family support or counselling	13.3 (6)	6.7 (3)	15.6 (7)	22.2 (10)	42.2 (19)
Additional supports for family members of individuals with ASD	33.3 (15)	2.2 (1)	13.3 (6)	17.8 (8)	33.3 (15)
Other services	58.5 (24)	0.0 (0)	7.3 (3)	4.9 (2)	29.3 (12)

NOTE: Dark yellow highlights indicate when greater than 50% of respondents indicated that a specific service or support was "Extremely Important". "OTHER SERVICES" described by respondents: help filling out forms; coordinator; financial support/counselling; specialized dental services; employment support; Adult ASD supports; post-secondary education support.

For caregivers of adults, many indicated that employment or adult day program services were "extremely important", in addition to other services highly relevant to adults such as life skills training and social skills/friendship programs.

Difficulty Obtaining "Extremely Important" Services and Supports (Overall) Percent (Number)			
Services and Supports	Not difficult	Moderately difficult	Very difficult
Early detection of ASD	25.2 (29)	42.6 (49)	32.2 (37)
Early ABA-based services for preschool children	11.1 (12)	41.7 (45)	47.2 (51)
Other forms of early intervention for preschool children (e.g., SLP, OT)	16.0 (17)	45.3 (48)	38.7 (41)
Daycare/preschool programs	20.0 (15)	50.7 (38)	29.3 (22)
Mainstream school supports	20.0 (29)	40.7 (59)	39.3 (57)
After-school supports	3.9 (3)	40.8 (31)	55.3 (42)
Recreational/leisure programs	19.7 (23)	43.6 (51)	36.8 (43)
Social skills/ friendship programs	9.2 (13)	38.0 (54)	52.8 (75)
Housing/residential options	11.3 (8)	21.1 (15)	67.6 (48)
Diagnostic and/or developmental/skill assessment services	14.3 (15)	44.8 (47)	41.0 (43)
Respite (in and/or out of home)	14.1 (12)	36.5 (31)	49.4 (42)
Specialized transportation	23.9 (11)	28.3 (13)	47.8 (22)
Mental health treatment	9.8 (9)	41.3 (38)	48.9 (45)
Medical services/care for adults	25.0 (16)	34.4 (22)	40.6 (26)
Crisis intervention/management	9.2 (6)	43.1 (28)	47.7 (31)
Behavioural intervention programs for behaviour management	9.1 (8)	39.8 (35)	51.1 (45)
Transition supports	14.7 (14)	41.1 (39)	44.2 (42)
Community safety training	7.8 (7)	42.2 (38)	50.0 (45)
Life skills training (e.g., money management, self-care, hygiene)	10.8 (13)	38.3 (46)	50.8 (61)
Post-secondary education programs (e.g., community college, university)	16.0 (17)	38.7 (41)	45.3 (48)
Employment or adult day programs	8.8 (9)	32.4 (33)	58.8 (60)
Parent/caregiver training programs	19.0 (16)	46.4 (39)	34.5 (29)
Family support or counselling	9.6 (8)	41.0 (34)	49.4 (41)
Additional supports for family members of individuals with ASD	8.6 (5)	37.9 (22)	53.4 (31)
Other services	12.8 (5)	20.5 (8)	66.7 (26)

NOTE: Dark yellow highlights indicate when greater than 50% of respondents indicated that a specific service or support was "Extremely Important". "OTHER SERVICES" described by respondents: counselling; follow-up; legal issues; financial planning; school supports; financial support; networking with other families; employment support; adult supports.

Across all age groups represented, for those services and supports that were identified as "extremely important" to caregivers, most indicated that these services were "moderately" to "very difficult" to obtain.

	How do you pay for "Extremely Important Services"? (Overall) Percent (Number)			
Services and Supports	Private (e.g., out of pocket)	Government	Private + Government	Not currently receiving
Early detection of ASD	27.2 (31)	39.5 (45)	12.3 (14)	21.1 (24)
Early ABA-based services for preschool children	24.3 (25)	25.2 (26)	20.4 (21)	30.1 (31)
Other forms of early intervention for preschool children (e.g., SLP, OT)	38.1 (40)	19.0 (20)	18.1 (19)	24.8 (26)
Daycare/preschool programs	45.9 (34)	6.8 (5)	9.5 (7)	37.8 (28)
Mainstream school supports	13.3 (19)	55.2 (79)	10.5 (15)	21.0 (30)
After-school supports	54.5 (42)	2.6 (2)	2.6 (2)	40.3 (31)
Recreational/leisure programs	58.3 (67)	7.8 (9)	14.8 (17)	19.1 (22)
Social skills/ friendship programs	40.3 (56)	8.6 (12)	12.9 (18)	38.1 (53)
Housing/residential options	26.0 (19)	6.8 (5)	9.6 (7)	57.5 (42)
Diagnostic and/or developmental/skill assessment services	33.0 (33)	29.0 (29)	11.0 (11)	27.0 (27)
Respite (in and/or out of home)	30.6 (26)	15.3 (13)	25.9 (22)	28.2 (24)
Specialized transportation	20.0 (9)	31.1 (14)	6.7 (3)	42.2 (19)
Mental health treatment	34.4 (31)	11.1 (10)	11.1 (10)	43.3 (39)
Medical services/care for adults	16.1 (10)	21.0 (13)	11.3 (7)	51.6 (32)
Crisis intervention/management	13.4 (9)	16.4 (11)	11.9 (8)	58.2 (39)
Behavioural intervention programs for behaviour management	22.7 (20)	22.7 (20)	11.4 (10)	43.2 (38)
Transition supports	23.4 (22)	17.0 (16)	16.0 (15)	43.6 (41)
Community safety training	22.7 (20)	10.2 (9)	5.7 (5)	61.4 (54)
Life skills training (e.g., money management, self-care, hygiene)	25.2 (30)	10.1 (12)	11.8 (14)	52.9 (63)
Post-secondary education programs (e.g., community college, university)	21.7 (23)	3.8 (4)	6.6 (7)	67.9 (72)
Employment or adult day programs	12.4 (13)	3.8 (4)	7.6 (8)	76.2 (80)
Parent/caregiver training programs	30.1 (25)	19.3 (16)	14.5 (12)	36.1 (30)
Family support or counselling	37.3 (31)	4.8 (4)	8.4 (7)	49.4 (41)
Additional supports for family members of individuals with ASD	39.0 (23)	5.1 (3)	8.5 (5)	47.5 (28)
Other services	39.0 (16)	2.4 (1)	7.3 (3)	51.2 (21)

NOTE: Dark yellow highlights = highest proportion of respondents who are currently receiving the specific service or support. Grey highlight = highest proportion of respondents overall are not currently receiving the service or support. "OTHER SERVICES" refer to those respondents described on previous page.

Examined across all age groups represented, majority of "extremely important" services were paid for privately.

How do you pay for "Extremely Important Services"? (0 – 17 years old) Percent (Number)				
Services and Supports	**Private (e.g., out of pocket)**	**Government**	**Private + Government**	**Not currently receiving**
Early detection of ASD	27.4 (26)	45.3 (43)	11.6 (11)	15.8 (15)
Early ABA-based services for preschool children	25.3 (22)	28.7 (25)	21.8 (19)	24.1 (21)
Other forms of early intervention for preschool children (e.g., SLP, OT)	38.6 (34)	21.6 (19)	19.3 (17)	20.5 (18)
Daycare/preschool programs	48.4 (30)	8.1 (5)	8.1 (5)	35.5 (22)
Mainstream school supports	13.4 (16)	61.3 (73)	9.2 (11)	16.0 (19)
After-school supports	53.8 (35)	3.1 (2)	3.1 (2)	40.0 (26)
Recreational/leisure programs	64.4 (58)	7.8 (7)	13.3 (12)	14.4 (13)
Social skills/ friendship programs	41.2 (47)	10.5 (12)	14.0 (16)	34.2 (39)
Housing/residential options	29.8 (14)	6.4 (3)	8.5 (4)	55.3 (26)
Diagnostic and/or developmental/skill assessment services	30.0 (24)	33.8 (27)	11.3 (9)	25.0 (20)
Respite (in and/or out of home)	30.4 (21)	17.4 (12)	26.1 (18)	26.1 (18)
Specialized transportation	15.2 (5)	36.4 (12)	9.1 (3)	39.4 (13)
Mental health treatment	31.3 (20)	9.4 (6)	9.4 (6)	50.0 (32)
Medical services/care for adults	14.0 (6)	16.3 (7)	9.3 (4)	60.5 (26)
Crisis intervention/management	14.6 (7)	12.5 (6)	10.4 (5)	62.5 (30)
Behavioural intervention programs for behaviour management	23.9 (17)	22.5 (16)	12.7 (9)	40.8 (29)
Transition supports	19.1 (13)	19.1 (13)	17.6 (12)	44.1 (30)
Community safety training	25.4 (18)	7.0 (5)	7.0 (5)	60.6 (43)
Life skills training (e.g., money management, self-care, hygiene)	27.2 (25)	7.6 (7)	10.9 (10)	54.3 (50)
Post-secondary education programs (e.g., community college, university)	16.5 (14)	3.5 (3)	4.7 (4)	75.3 (64)
Employment or adult day programs	8.1 (6)	2.7 (2)	5.4 (4)	83.8 (64)
Parent/caregiver training programs	27.5 (19)	23.2 (16)	15.9 (11)	33.3 (23)
Family support or counselling	29.2 (19)	4.6 (3)	10.8 (7)	55.4 (36)
Additional supports for family members of individuals with ASD	34.8 (16)	6.5 (3)	8.7 (4)	50.0 (23)
Other services	40.0 (12)	0.0 (0)	6.7 (2)	53.3 (16)

NOTE: Dark yellow highlights = highest proportion of respondents who are currently receiving the specific service or support. Grey highlight = highest proportion of respondents overall are not currently receiving the service or support.
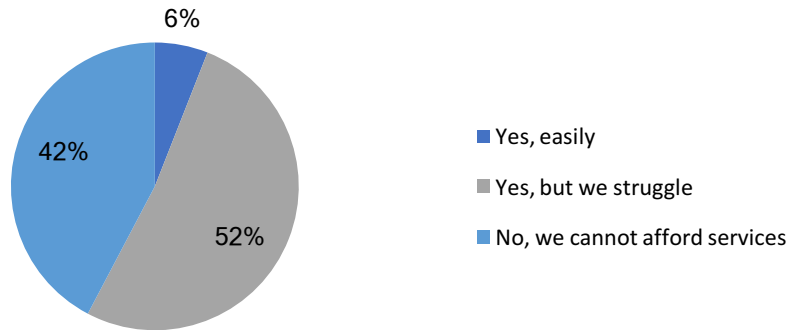
Majority of caregivers representing children reported that "extremely important" services were paid for privately, through government support, or a combination of the two. In several categories, caregivers said they did not currently receive those services. It remains unclear whether services were not received due to access/financial reasons, or simply because they were not necessary for their sons/daughters at the time of the survey, or other reasons.

How do you pay for "Extremely Important Services"? (18 years old and over) Percent (Number)				
Services and Supports	Private (e.g., out of pocket)	Government	Private + Government	Not currently receiving
Early detection of ASD	26.3 (5)	10.5 (2)	15.8 (3)	47.4 (9)
Early ABA-based services for preschool children	18.8 (3)	6.3 (1)	12.5 (2)	62.5 (10)
Other forms of early intervention for preschool children (e.g., SLP, OT)	35.3 (6)	5.9 (1)	11.8 (2)	47.1 (8)
Daycare/preschool programs	33.3 (4)	0.0 (0)	16.7 (2)	50.0 (6)
Mainstream school supports	12.5 (3)	25.0 (6)	16.7 (4)	45.8 (11)
After-school supports	58.3 (7)	0.0 (0)	0.0 (0)	41.7 (5)
Recreational/leisure programs	36.0 (9)	8.0 (2)	20.0 (5)	36.0 (9)
Social skills/ friendship programs	36.0 (9)	0.0 (0)	8.0 (2)	56.0 (14)
Housing/residential options	19.2 (5)	7.7 (2)	11.5 (3)	61.5 (16)
Diagnostic and/or developmental/skill assessment services	45.0 (9)	10.0 (2)	10.0 (2)	35.0 (7)
Respite (in and/or out of home)	31.3 (5)	6.3 (1)	25.0 (4)	37.5 (6)
Specialized transportation	33.3 (4)	16.7 (2)	0.0 (0)	50.0 (6)
Mental health treatment	42.3 (11)	15.4 (4)	15.4 (4)	26.9 (7)
Medical services/care for adults	21.1 (4)	31.6 (6)	15.8 (3)	31.6 (6)
Crisis intervention/management	10.5 (2)	26.3 (5)	15.8 (3)	47.4 (9)
Behavioural intervention programs for behaviour management	17.6 (3)	23.5 (4)	5.9 (1)	52.9 (9)
Transition supports	34.6 (9)	11.5 (3)	11.5 (3)	42.3 (11)
Community safety training	11.8 (2)	23.5 (4)	0.0 (0)	64.7 (11)
Life skills training (e.g., money management, self-care, hygiene)	18.5 (5)	18.5 (5)	14.8 (4)	48.1 (13)
Post-secondary education programs (e.g., community college, university)	42.9 (9)	4.8 (1)	14.3 (3)	38.1 (8)
Employment or adult day programs	22.6 (7)	6.5 (2)	12.9 (4)	58.1 (18)
Parent/caregiver training programs	42.9 (6)	0.0 (0)	7.1 (1)	50.0 (7)
Family support or counselling	66.7 (12)	5.6 (1)	0.0 (0)	27.8 (5)
Additional supports for family members of individuals with ASD	53.8 (7)	0.0 (0)	7.7 (1)	38.5 (5)
Other services	36.4 (4)	9.1 (1)	9.1 (1)	45.5 (5)

NOTE: Dark yellow highlights = highest proportion of respondents who are currently receiving the specific service or support. Grey highlight = highest proportion of respondents overall are not currently receiving the service or support.

Majority of caregivers representing adults reported that "extremely important" services were paid for privately, through government support, or a combination of the two. In several categories caregivers said they did not currently receive those services. It remains unclear whether services were not received due to access/financial reasons, or simply because they were not necessary for their sons/daughters at the time of the survey, or other reasons.

In general can you afford to pay for services?
(*n* = 201)

Legend:
- ■ Yes, easily
- ■ Yes, but we struggle
- ■ No, we cannot afford services

Majority of caregivers said that they could afford services but that it was a struggle. A large proportion of caregivers could not afford services.

Has the person you're representing ever completed a DSO Assessment?
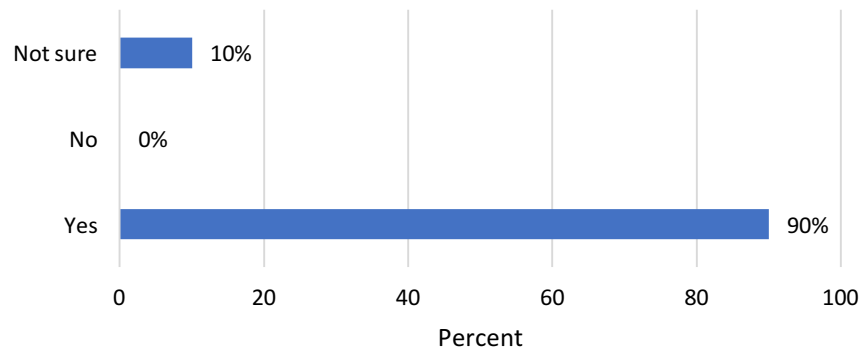### (18 years and older; *n* = 46)
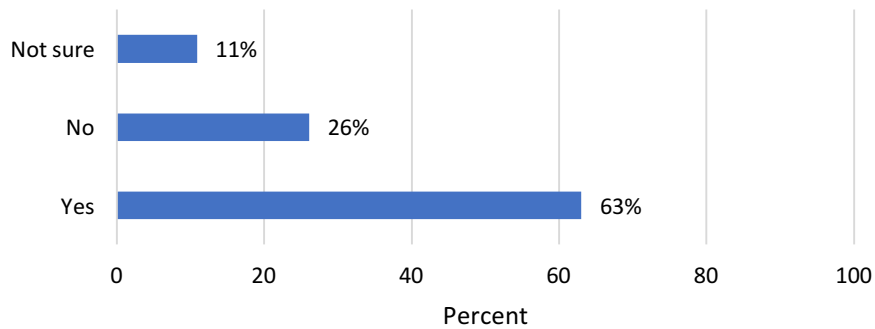
For caregivers of adult children, majority completed a DSO assessment at some point.

Passport funding ever received?
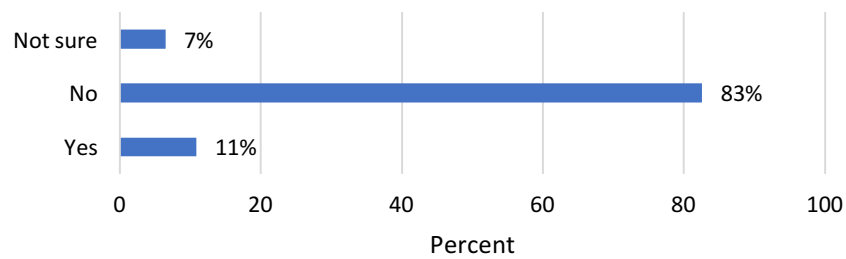### (18 years and older; *n* = 46)
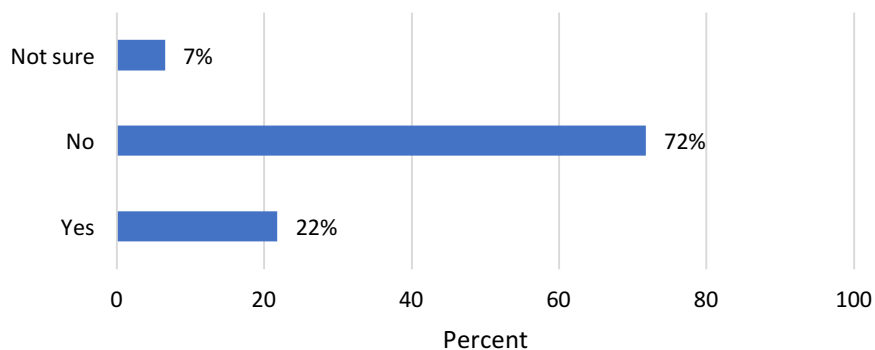
For caregivers of adult children, majority never received Passport funding.

Currently receiving Passport funding?
(18 years and older; *n* = 10)

|	Percent
Not sure	10%
No	0%
Yes	90%

For caregivers who reported that their adult children had received Passport funding, majority were currently receiving it.

Ever used Passport funding to access
services through DSO?
(18 years and older; *n* = 46)

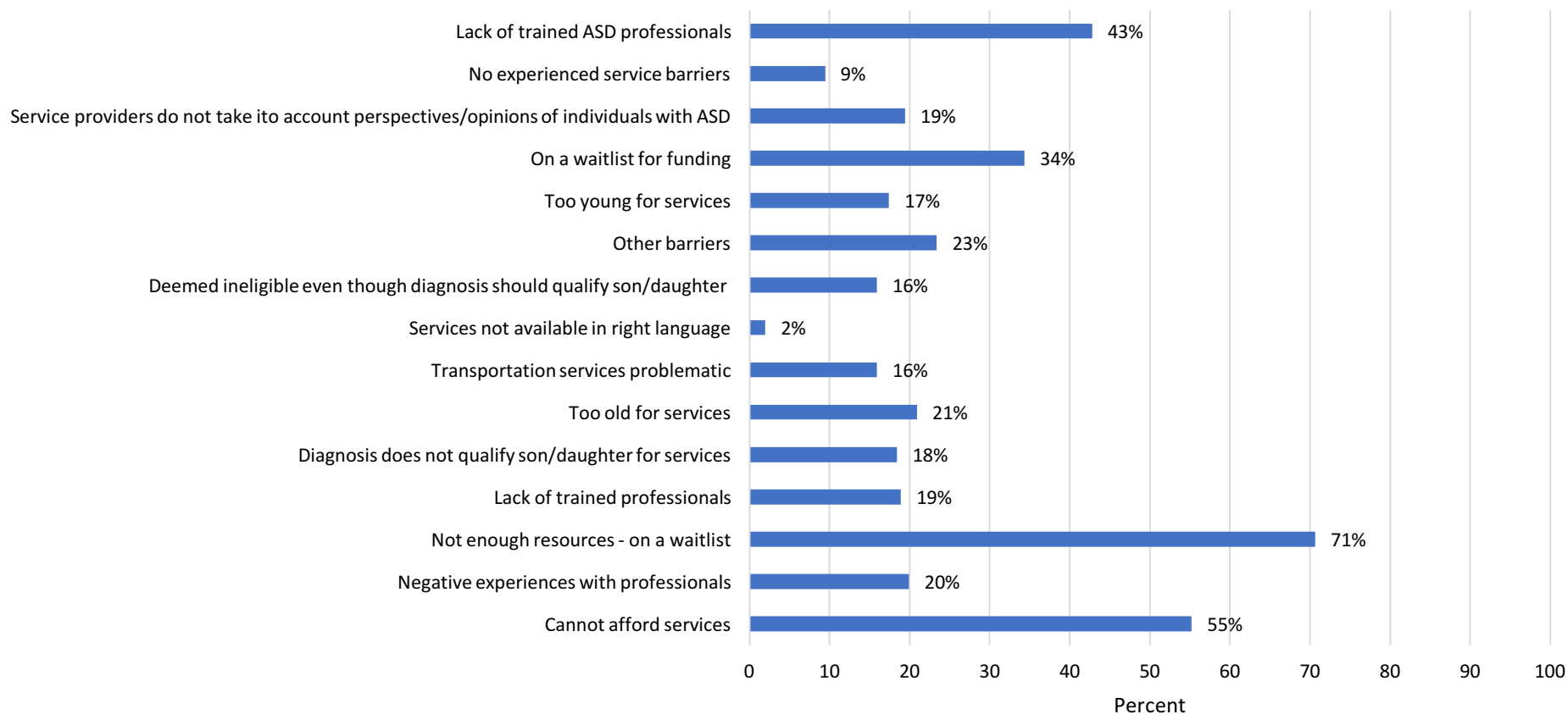|	Percent
Not sure	7%
No	83%
Yes	11%

For caregivers of adult children, the majority had not used Passport funding to access services through DSO.

Currently accessing services through DSO?
(18 years and older; *n* = 46)

	Percent
Not sure	7%
No	67%
Yes	26%
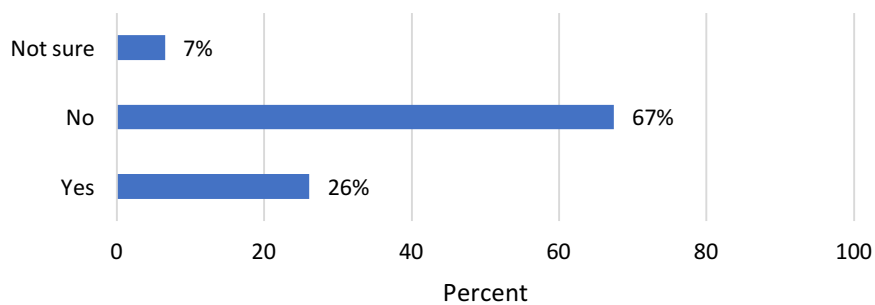
For caregivers of adult children, the majority were not currently accessing services through DSO.

Caregiver reported barriers (*n* = 201)

Barrier	Percent
Lack of trained ASD professionals	43%
No experienced service barriers	9%
Service providers do not take ito account perspectives/opinions of individuals with ASD	19%
On a waitlist for funding	34%
Too young for services	17%
Other barriers	23%
Deemed ineligible even though diagnosis should qualify son/daughter	16%
Services not available in right language	2%
Transportation services problematic	16%
Too old for services	21%
Diagnosis does not qualify son/daughter for services	18%
Lack of trained professionals	19%
Not enough resources - on a waitlist	71%
Negative experiences with professionals	20%
Cannot afford services	55%

Percent

OTHER BARRIERS: professionals across disciplines not working together; challenges with getting a diagnosis; son/daughter perceived to not need supports; no available services in the area; lack of funding/financial issues; timing and availability of services; hard to find services that do not match functioning level; limited information on available services; caregivers are too tired/too old; son's/daughter's issues not viewed as severe enough for immediate service; son/daughter does not way service; aggressive behaviours; inflexibility of services available (i.e., times offered); no in-school services; long waitlists.

Across all age groups, over 70% of caregivers reported that being on waitlists was a barrier. Language barriers were experienced by a minority in our sample. Less than 10% of the sample reported that they experienced no barriers to service access.

Importance Ratings of Seamless Service Transition Components Percent (Number)					
Services and Supports	Not at all important	A little important	Moderately important	Very important	Extremely important
Support from specialized transition team	5.1 (10)	11.1 (22)	15.7 (31)	32.8 (65)	35.4 (70)
Support from specialized transition coordinator (single contact person)	4.6 (9)	5.6 (11)	18.3 (36)	28.9 (57)	42.6 (84)
Early transition planning	5.1 (10)	4.6 (9)	13.2 (26)	31.5 (62)	45.7 (90)
Individualized and comprehensive transition plan	4.6 (9)	6.6 (13)	10.7 (21)	31.0 (61)	47.2 (93)
Communication between pre- and post-transition professionals	5.6 (11)	3.0 (6)	12.6 (25)	32.3 (64)	46.5 (92)
Post-transition follow-up	5.1 (10)	3.5 (7)	15.7 (31)	33.8 (67)	41.9 (83)
Family engagement in transition planning and/or transition process	5.1 (10)	1.5 (3)	9.1 (18)	34.0 (67)	50.3 (99)
Engagement of individual with ASD in transition planning and/or transition process	6.1 (12)	5.1 (10)	15.3 (30)	29.6 (58)	43.9(86)

Other components described by participants: follow up; Knowledgeable staff such as coordinator to respond to questions; school as a setting for services; transition supports at various ages; Case manager; Housing; Transition coordinator who is sensitive to needs/unique circumstances; Single case coordinator

Many caregivers indicated that the components listed for a seamless service transition were "extremely important".

Perceived efficiency of current York Region ASD service system (*n* = 202)
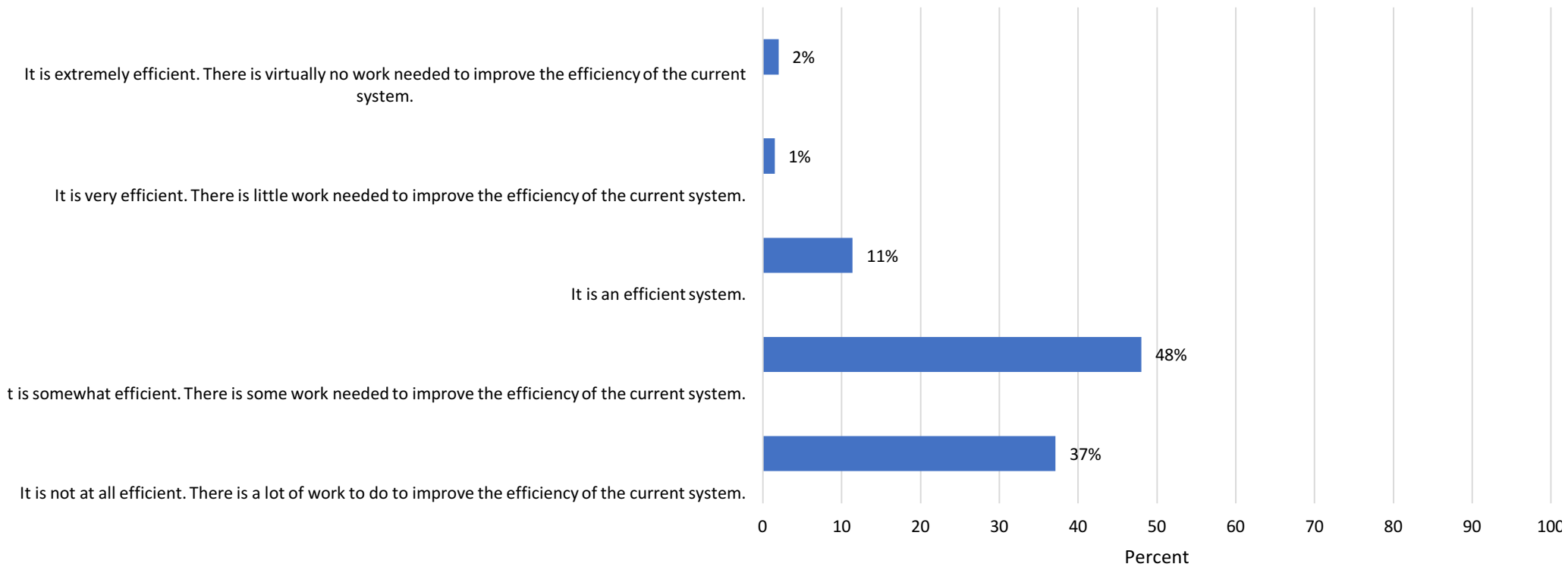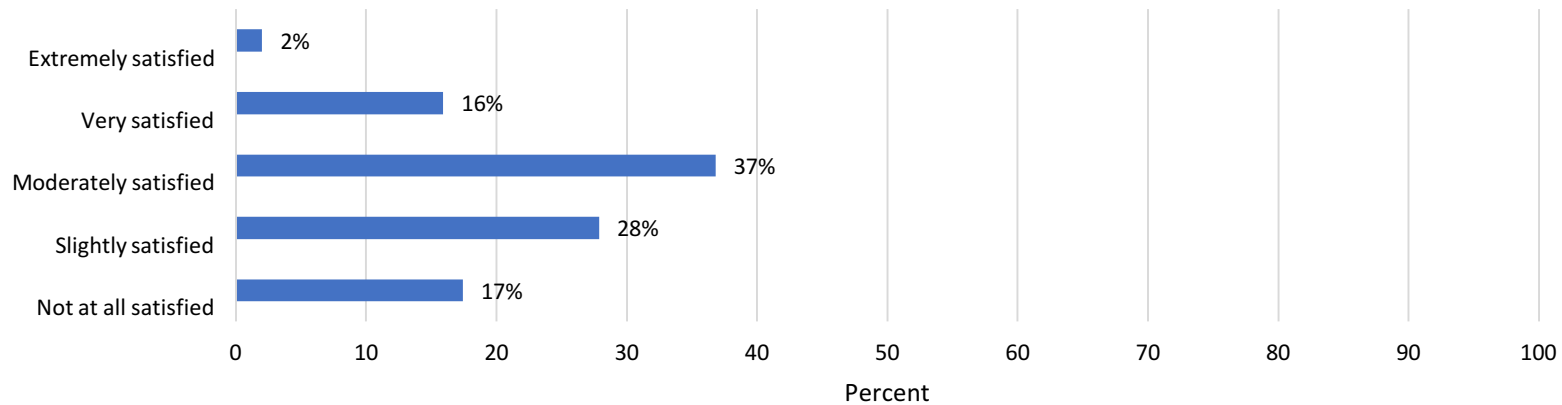

Overall, nearly half of all caregivers described the current York Region ASD service system as being "somewhat efficient" and indicated that there is some work needed to improve its efficiency. A minority of respondents indicated that at current, it is an "efficient" to "extremely efficient" system.

Overall quality of available York Region ASD services (*n* = 202)

- Excellent — 2%
- Very Good — 6%
- Good — 35%
- Fair — 31%
- Poor — 26%

Percent
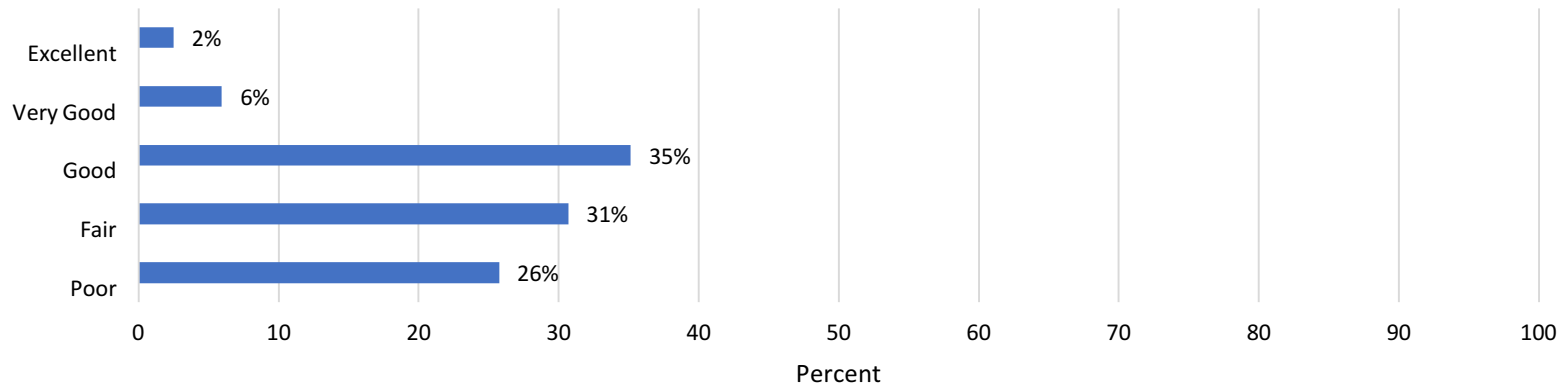
Majority of caregivers reported that the overall quality of currently available York Region ASD services was "fair" to "good". A minority indicated that available services were "very good" to "excellent".

Caregiver satisfaction with ASD services accessed in York Region (*n* = 201)

- Extremely satisfied — 2%
- Very satisfied — 16%
- Moderately satisfied — 37%
- Slightly satisfied — 28%
- Not at all satisfied — 17%

Percent

Overall, majority of caregivers reported that they were either "slightly" or "moderately satisfied" with the ASD services they accessed in York Region. Few respondents were "extremely satisfied" with services accessed.

PROFESSIONAL SURVEY RESULTS

DEMOGRAPHIC INFORMATION:

Length of time working in field of ASD (*n* = 154)
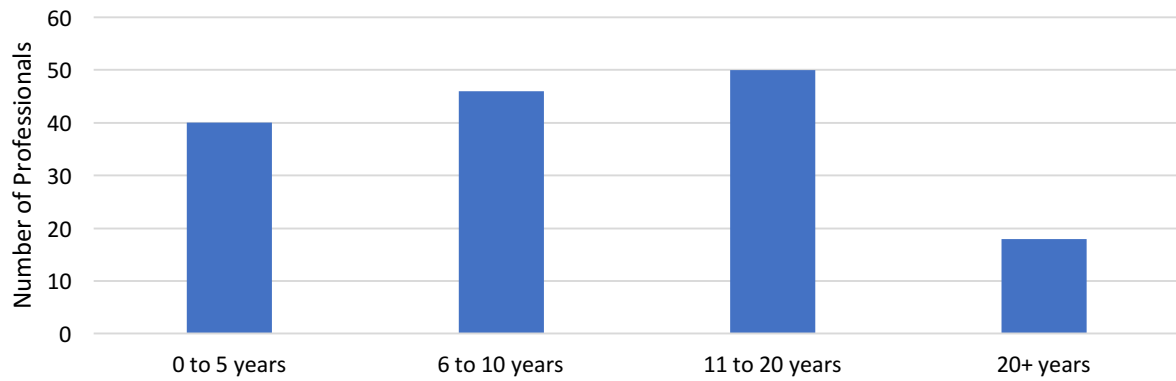
Profession (*n* = 154)
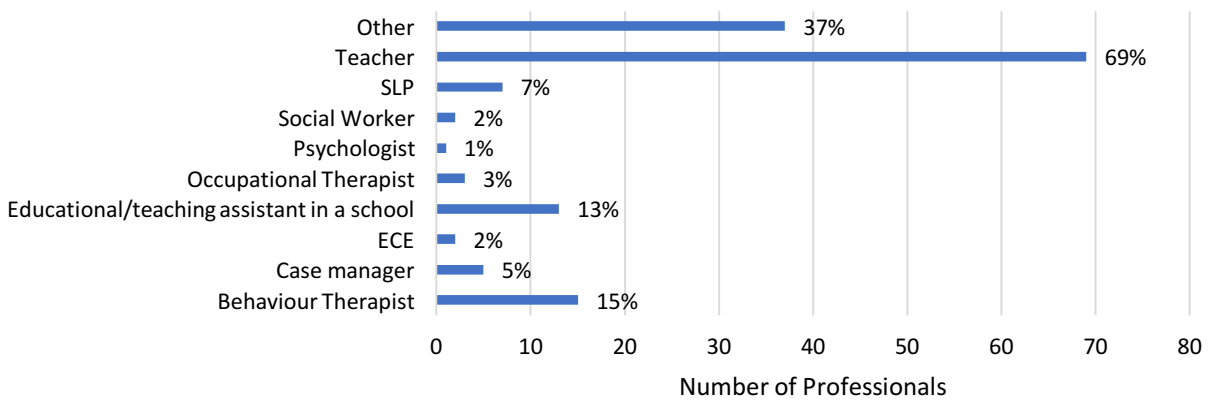
Other Professionals: School administrators; Principals and vice principals; Early Interventionists; ABA facilitators; ASD Consultants; Family support navigators; Life coaches; CYWs; Guidance counsellors

Majority of professionals who responded to this survey were educators (mainly teachers), which is important to consider when interpreting the results below.

Age groups with whom professionals work (*n* = 154)
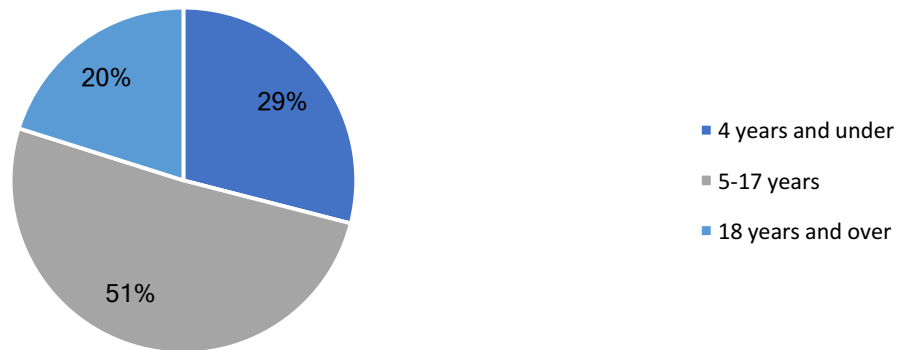
Majority of professionals worked with youth between the ages of 5 to 17 years old.

York Region areas where professionals work (*n* = 154)
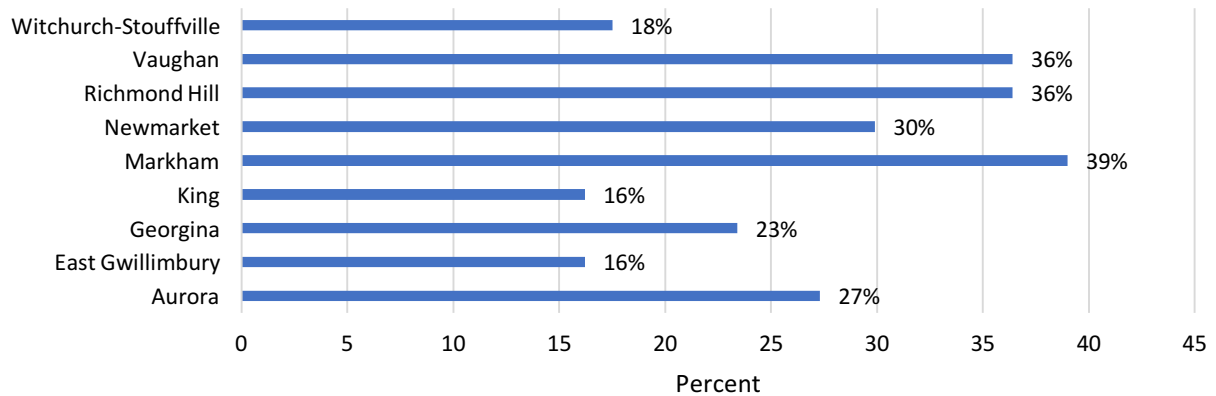
Professionals representing all nine areas of York Region participated in this survey.

Services and Supports	Not at all important	A little important	Moderately important	Very important	Extremely important
Importance Ratings of Various Services and Supports **Percent (Number)**					
Early detection of ASD	0.7 (1)	1.3 (2)	2.6 (4)	21.6 (33)	73.9 (113)
Early ABA-based services for preschool children	1.3 (2)	2.6 (4)	9.2 (14)	20.9 (32)	66.0 (101)
Other forms of early intervention for preschool children (e.g., SLP, OT)	1.3 (2)	0.7 (1)	3.3 (5)	28.1 (43)	66.7 (102)
Daycare/preschool programs	2.0 (3)	1.3 (2)	15.7 (24)	32.7 (50)	48.4 (74)
Mainstream school supports	0.0 (0)	2.0 (3)	3.9 (6)	30.9 (47)	63.2 (96)
After-school supports	0.0 (0)	2.6 (4)	19.0 (29)	29.4 (45)	49.0 (75)
Recreational/leisure programs	0.0 (0)	0.7 (1)	10.5 (16)	34.0 (52)	54.9 (84)
Social skills/ friendship programs	0.0 (0)	0.0 (0)	3.9 (6)	27.5 (42)	68.6 (105)
Housing/residential options	3.9 (6)	2.6 (4)	15.1 (23)	30.9 (47)	47.4 (72)
Diagnostic and/or developmental/skill assessment services	0.0 (0)	0.7 (1)	7.2 (11)	26.1 (40)	66.0 (101)
Respite (in and/or out of home)	2.0 (3)	1.3 (2)	11.8 (18)	31.4 (48)	53.6 (82)
Specialized transportation	1.3 (2)	4.6 (7)	23.5 (36)	38.6 (59)	32.0 (49)
Mental health treatment	0.0 (0)	1.3 (2)	2.0 (3)	25.7 (39)	71.1 (108)
Medical services/care for adults	2.6 (4)	2.0 (3)	10.6 (16)	39.1 (59)	45.7 (69)
Crisis intervention/management	0.0 (0)	1.3 (2)	5.9 (9)	31.6 (48)	61.2 (93)
Behavioural intervention programs for behaviour management	0.0 (0)	0.7 (1)	3.9 (6)	22.2 (34)	73.2 (112)
Transition supports	0.0 (0)	0.7 (1)	6.6 (10)	35.5 (54)	57.2 (87)
Community safety training	0.7 (1)	0.0 (0)	10.5 (16)	34.2 (52)	54.6 (83)
Life skills training (e.g., money management, self-care, hygiene)	0.7 (1)	0.0 (0)	7.2 (11)	27.6 (42)	64.5 (98)
Post-secondary education programs (e.g., community college, university)	2.6 (4)	2.0 (3)	13.8 (21)	31.6 (48)	50.0 (76)
Employment or adult day programs	2.0 (3)	0.7 (1)	7.3 (11)	29.1 (44)	60.9 (92)
Parent/caregiver training programs	0.7 (1)	0.0 (0)	5.2 (8)	26.1 (40)	68.0 (104)
Family support or counselling	0.7 (1)	0.7 (1)	6.5 (10)	30.7 (47)	61.4 (94)
Additional supports for family members of individuals with ASD	29.1 (43)	2.0 (3)	10.8 (16)	25.0 (37)	33.1 (49)
Other services	58.7 (84)	3.5 (5)	5.6 (8)	10.5 (15)	21.7 (31)

"OTHER SERVICES" described by respondents: extended & other family member support; school transition support; dual diagnosis support; community education; summer programs; case management; financial support; respite; multicultural support.
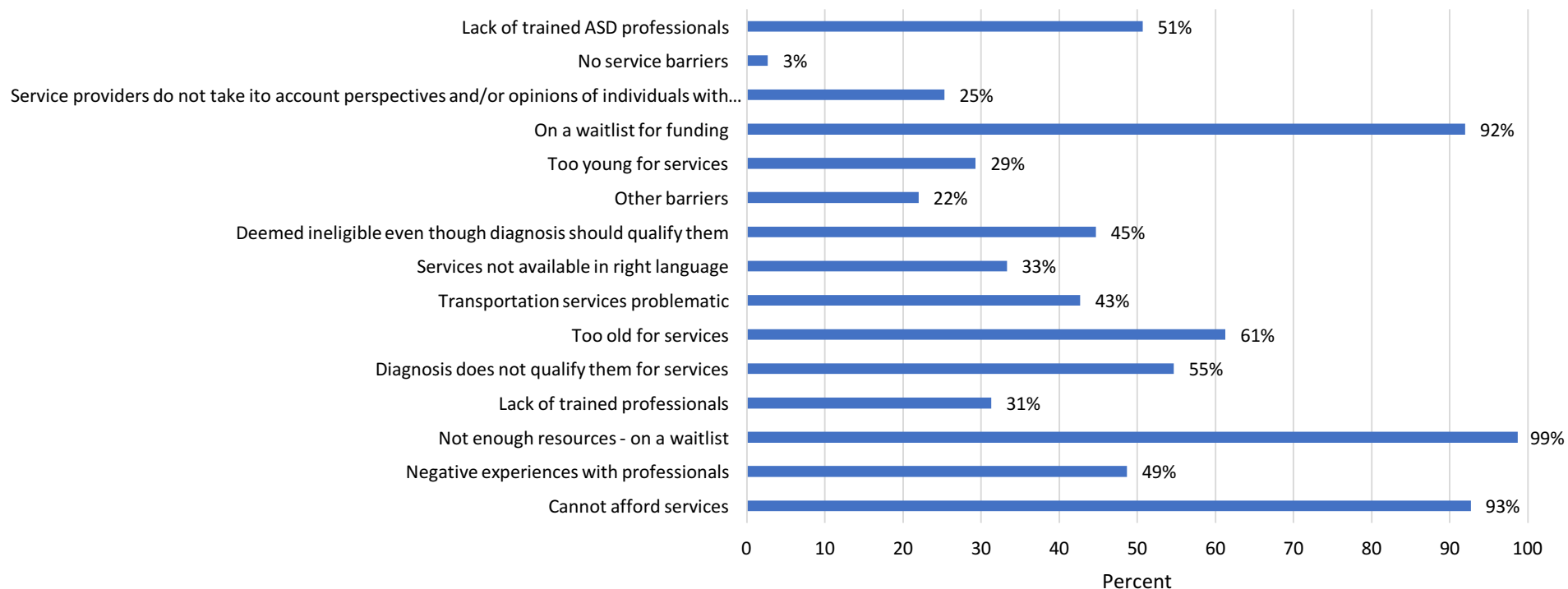
Professionals endorsed many services across the lifespan as "extremely important" for the individuals with whom they work and their families.

How do caregivers/individuals with ASD pay for "Extremely Important" Services? Percent (Number)		
Services and Supports	**Private (e.g., out of pocket)**	**Government**	**Private + Government**
Early detection of ASD	11.0 (12)	29.4 (32)	59.6 (65)
Early ABA-based services for preschool children	23.0 (23)	19.0 (19)	58.0 (58)
Other forms of early intervention for preschool children (e.g., SLP, OT)	23.0 (23)	12.0 (12)	65.0 (65)
Daycare/preschool programs	43.7 (31)	4.2 (3)	52.1 (37)
Mainstream school supports	2.2 (2)	82.6 (76)	15.2 (14)
After-school supports	45.1 (32)	5.6 (4)	49.3 (35)
Recreational/leisure programs	60.5 (49)	3.7 (3)	35.8 (29)
Social skills/ friendship programs	38.6 (39)	14.9 (15)	46.5 (47)
Housing/residential options	20.6 (14)	8.8 (6)	70.6 (48)
Diagnostic and/or developmental/skill assessment services	10.4 (10)	20.8 (20)	68.8 (66)
Respite (in and/or out of home)	14.1 (11)	10.3 (8)	75.6 (59)
Specialized transportation	23.4 (11)	25.5 (12)	51.1 (24)
Mental health treatment	21.4 (22)	20.4 (21)	58.3 (60)
Medical services/care for adults	11.9 (8)	44.8 (30)	43.3 (29)
Crisis intervention/management	18.7 (17)	27.5 (25)	53.8 (49)
Behavioural intervention programs for behaviour management	16.4 (18)	22.7 (25)	60.9 (67)
Transition supports	15.3 (13)	25.9 (22)	58.8 (50)
Community safety training	29.1 (23)	22.8 (18)	48.1 (38)
Life skills training (e.g., money management, self-care, hygiene)	21.3 (20)	18.1 (17)	60.6 (57)
Post-secondary education programs (e.g., community college, university)	27.4 (20)	20.5 (15)	52.1 (38)
Employment or adult day programs	29.2 (26)	12.4 (11)	58.4 (52)
Parent/caregiver training programs	25.0 (25)	22.0 (22)	53.0 (53)
Family support or counselling	34.4 (31)	6.7 (6)	58.9 (53)
Additional supports for family members of individuals with ASD	39.5 (17)	9.3 (4)	51.2 (22)
Other services	41.4 (12)	17.2 (5)	41.4 (12)

"OTHER SERVICES" described by respondents: (as described on previous page).

Professionals reported that individuals with ASD and their families paid for "extremely important" services mainly through a combination of private and government funding.

Professional barriers (*n* = 150)

Barrier	Percent
Lack of trained ASD professionals	51%
No service barriers	3%
Service providers do not take ito account perspectives and/or opinions of individuals with…	25%
On a waitlist for funding	92%
Too young for services	29%
Other barriers	22%
Deemed ineligible even though diagnosis should qualify them	45%
Services not available in right language	33%
Transportation services problematic	43%
Too old for services	61%
Diagnosis does not qualify them for services	55%
Lack of trained professionals	31%
Not enough resources - on a waitlist	99%
Negative experiences with professionals	49%
Cannot afford services	93%

Percent

OTHER BARRIERS: income cutoffs for funding; service not available in geographic area; maladaptive behaviours; lack of support to complete applications; lack of support for those with dual diagnosis; families do not know where to go for services/navigation difficulties; ineligible for DSO services or other financial supports; cultural barriers.

Nearly all professionals reported that waitlists and affordability of services were barriers to service access. A very small number of professionals stated no perceived service barriers for families.

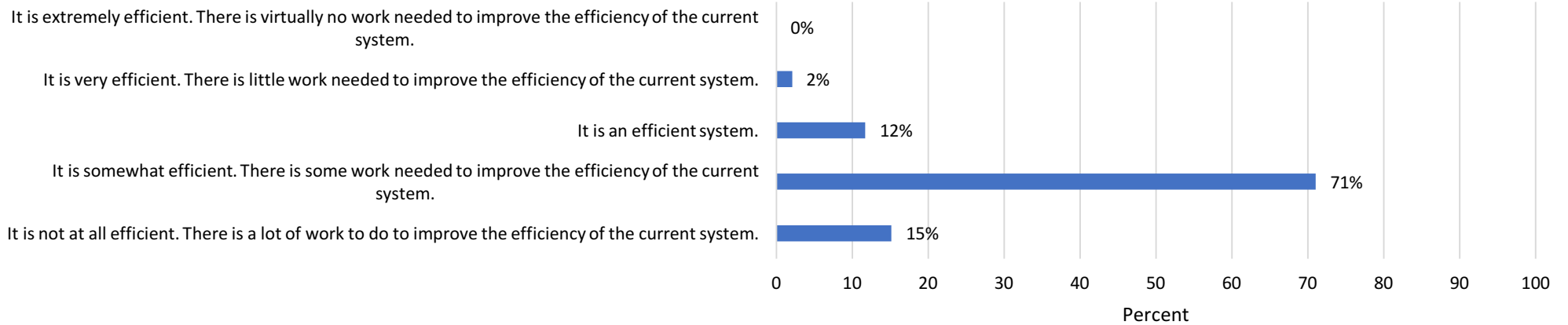| Importance Ratings of Seamless Service Transition Components Percent (Number)					
Services and Supports	**Not at all important**	**A little important**	**Moderately important**	**Very important**	**Extremely important**
Support from specialized transition team	0.0 (0)	4.8 (7)	19.0 (28)	37.4 (55)	38.8 (57)
Support from specialized transition coordinator (single contact person)	0.7 (1)	4.8 (7)	14.3 (21)	38.8 (57)	41.5 (61)
Early transition planning	0.0 (0)	0.7 (1)	8.2 (12)	37.4 (55)	53.7 (79)
Individualized and comprehensive transition plan	0.0 (0)	0.7 (1)	8.2 (12)	39.5 (58)	51.7 (76)
Communication between pre- and post-transition professionals	0.0 (0)	0.0 (0)	6.8 (10)	40.1 (59)	53.1 (78)
Post-transition follow-up	0.0 (0)	2.0 (3)	14.3 (21)	39.5 (58)	44.2 (65)
Family engagement in transition planning and/or transition process	0.0 (0)	0.7 (1)	4.1 (6)	26.5 (39)	68.7 (101)
Engagement of individual with ASD in transition planning and/or transition process	0.0 (0)	1.4 (2)	12.9 (19)	32.7 (48)	53.1(78)

Other components: Opportunities for all team members (e.g., teachers and EA) to attend family meetings; Regular communication between community transition team and schools; Professional support service for those with dual diagnoses; Trained transition teams for specific age groups; Translation services/multicultural support; Daily living skills training.

Professionals indicated that several of the components listed were "very important" to "extremely important" for a seamless service transition including: early transition planning, an individualized plan, engaging the family/individual with ASD, and communication between transition groups.

| Do These Service Transition Components Exist in York Region? Percent (Number)				
Services and Supports	**Not at all**	**Somewhat**	**Definitely**	**Not sure**
Support from specialized transition team	8.3 (12)	40.0 (58)	33.1 (48)	18.6 (27)
Support from specialized transition coordinator (single contact person)	9.7 (14)	39.3 (57)	28.3 (41)	22.8 (33)
Early transition planning	2.8 (4)	45.5 (66)	35.2 (51)	16.6 (24)
Individualized and comprehensive transition plan	4.8 (7)	50.3 (73)	29.0 (42)	15.9 (23)
Communication between pre- and post-transition professionals	9.7 (14)	49.7 (72)	22.8 (33)	17.9 (26)
Post-transition follow-up	21.4 (31)	47.6 (69)	11.0 (16)	20.0 (29)
Family engagement in transition planning and/or transition process	2.8 (4)	46.9 (68)	33.8 (49)	16.6 (24)
Engagement of individual with ASD in transition planning and/or transition process	11.1 (16)	53.5 (77)	16.7 (24)	18.8 (27)

When asked whether the transition components listed on the previous page exist in York Region, many professionals stated that they at minimum "somewhat" exist.

Perceived efficiency of current York Region ASD service system (*n* = 145)

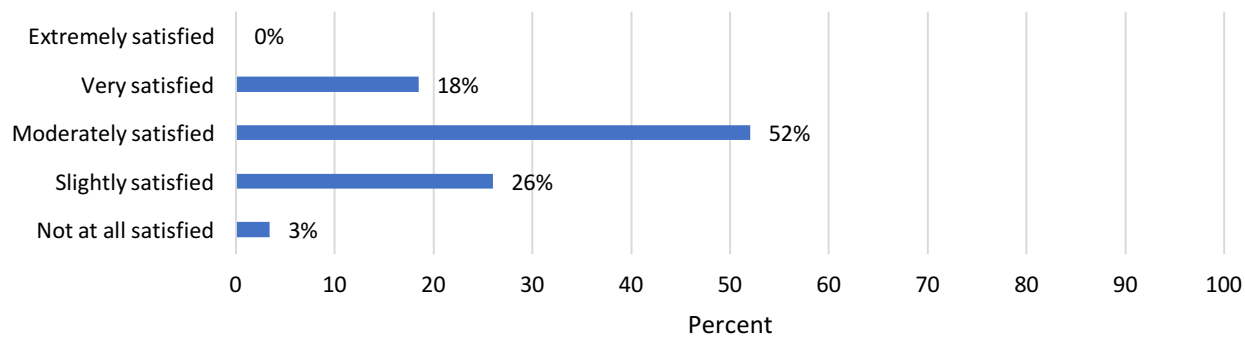| Response	Percent
It is extremely efficient. There is virtually no work needed to improve the efficiency of the current system.	0%
It is very efficient. There is little work needed to improve the efficiency of the current system.	2%
It is an efficient system.	12%
It is somewhat efficient. There is some work needed to improve the efficiency of the current system.	71%
It is not at all efficient. There is a lot of work to do to improve the efficiency of the current system.	15%

Percent

Majority of professionals described the current York Region ASD service system as being "somewhat efficient" and indicated that there is some work needed to improve its efficiency. A minority of respondents indicated that it is "very efficient" and no one perceived it to be an "extremely efficient" system of services and supports.

Overall quality of available York Region ASD services (*n* = 146)

Rating	Percent
Excellent	1%
Very Good	10%
Good	45%
Fair	40%
Poor	5%

Percent
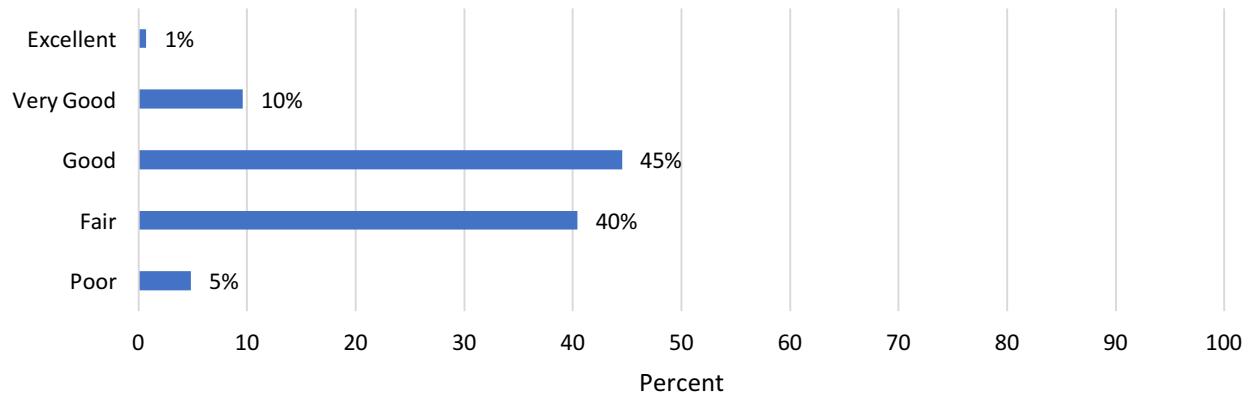
Over 80% of professionals indicated that the overall quality of currently available York Region services was "fair" to "good".

Overall satisfaction with services accessed in York Region (*n* = 146)

Rating	Percent
Extremely satisfied	0%
Very satisfied	18%
Moderately satisfied	52%
Slightly satisfied	26%
Not at all satisfied	3%

Percent

More than half of professionals were "moderately satisfied" with services accessed by the individuals and families with whom they work.

PRELIMINARY QUALITATIVE FINDINGS
Sample quotes of open-ended comments questions

CAREGIVERS:

- **<u>Early intervention is stressed, yet long waitlists</u>**
  - o "The services are great; well planned out and organised however, it is repeatedly stressed too us how important early intervention is but the waiting list for programs are 2-3 years long! What else can we do other than pay out of pocket? Struggling or not! Also, the fact that once you reach a certain "goal" you're then put back on another waiting list! The backbone is there for a great program but there is much to be done regarding the abundance of those in need and the number of people who actually receive the help!"

- **<u>Lack of funding is frustrating</u>**
  - o "Unfortunately in this system you have to keep advocating for your child to get faster efficient and accurate services. It is very frustrating process as my parents feel the huge stress to deal with the lack of funding, the lack of communication to parents on what steps to take once diagnosis, no guidance on where to get extra funding and help for their child…"

- **<u>Need for post-secondary supports</u>**
  - o "Schools also require supports to help these students transition to either their post-secondary destinations or into the workforce. It feels like a dead-end once high school is over. Grants for employers to hire these individuals, training and post-secondary supports are where more money should be allocated."

- **<u>Feeling hopeless</u>**
  - o "My child is transitioning from high school to community. Is waitlisted for passport funding. Have been told they will place her in an available subsidized spot - not a program suited to her needs. Her needs are significant….When I call … to inquire about potential passport funding, have been repeatedly told Ministry has not released funds. No other options for care provided other than "perhaps" we can access [other funds] to bathe her once a week. I feel because she doesn't have a voice she is invisible, less than, not worthy of a decent quality of life, not given choices or treated with dignity. She is just a number on a list."
  - o "…I've given up hoping that anything will be in place in time to help [child]. Right now I'm focused on trying to get him through regular high school without anymore psychological damage."

- **<u>Waitlists</u>**
  - o "We are very lucky in terms of having an Early Interventionist who has a great understanding of ASD and the community. We are also lucky to have contact

with [treatment organization] which has also been an excellent resource and teaching point.   Apart from that the ASD system is nothing but wait list after wait list. There are very limited options available outside of the government and the ones that are out there are so expensive only a very select few can afford to enroll their children in them. It is very frustrating as a parent to see you child struggling, and to be practically begging for help, but all that you receive is someone telling you that 'things will get better' and then being put on multiple (over 2 year long) wait lists.   There needs to be major change implemented into the ASD system in which children are receiving the treatment they need, without having to wait years to get it."

- o "wait list are too long and I feel like you have to jump through hoops to get help."

- **Difficult to locate services**
  - o "Services are hard to locate and to know what you do qualify for and who to contact."

- **Siloed agencies**
  - o "In spite of work being done, it can be extremely hard to know who to go to, and what specific questions to ask, in order to receive services. Agencies are still siloed and don't seem to know what each other does."

- **Lacking services for higher functioning individuals**
  - o "Definite lack of services for higher functioning individuals who require support with post-secondary education, life skills, and employment. Focus at the early intervention stage is critical but so is assisting the individual struggling with integration into an adult world. Assistance seems to be geared towards those with more obvious disabilities. It is tough to help our son navigate his challenges while protecting his dignity and privacy."

- **Privilege**
  - o "Our family has been very fortunate because we have been able to advocate and navigate a very complex system. We are educated parents, born and raised in this country, who remain married, who have good jobs, and who have lots of currency, simply because of our unearned privilege. The reality is that most of our families do not have the advantages that we have."

SELF-ADVOCATES:

- **<u>Services do not exist, and if they do, they are costly</u>**
  - "The services don't exist or may if you can afford to pay lots of money."

- **<u>Housing is problematic</u>**
  - "the housing of adults with autism and other special needs is woefully inadequate. The need to give quality support to individuals who require ongoing life skills and cannot live long term with aging parents is absolutely huge. As well, the process of finally getting into such appropriate housing is a huge barrier, which requires a time-consuming competitive process between applicants. It takes a huge toll on the clients and their families. Much must be done to make this situation more accessible and equitable."

  - "There is also a lack of suitable housing options for the young adult whose parents can no longer care for them and for who supported living is not an option. group home lists are horrendously long."

- **<u>Services geared toward children</u>**
  - "Main issue, not probably fixable, is services are geared to parents and kids / young adults with ASD, not me."

- **<u>Need more trained health care professionals</u>**
  - "Our main issues are lack of medical services by qualified people and inability to access them due to aging out."

PROFESSIONALS:

- **Funding issues**
  - "there are insufficient publicly funded intervention services for children once diagnosed, which extends through school age. There are almost no publicly funded services available for adults with ASD, and many are ineligible for the available community supports, due to their diagnosis"

- **Training for health care professionals**
  - "There needs to be medical and emergency professionals that are trained to work with families and the people with ASD. It is difficult for some people with ASD to have medical appointments and emergency room visits due to sensory and behavioral issues."

- **Mental health**
  - "There are not enough supports put into place for students with ASD and mental health issues."

- **Information sharing across systems of care**
  - "We need to do a better job of sharing services and of information so parents are not forced to repeat their story over and over again."

- **Insufficient number of services to meet regional needs**
  - "There are local experts in York Region across all sectors of service delivery. There are not enough services to meet the needs of the region."

- **Early and integrated planning is necessary**
  - "Agencies need to work more collaboratively and across sectors (e.g., across DS and Mental Health) to support the individual/family. Planning needs to be more integrated and earlier when approaching transitions."

- **Waitlists**
  - "Waiting lists are way too long, families have difficulty accessing services, too many different agencies to navigate and to know what they do…"

- **Fragmented transition process to adult services**
  - "Transitioning these clients from high school to adult services is frustrating at best. I find agencies say they offer services only to find out when accessing they do not. I feel sorry for families with ASD. I witness their daily struggles supporting their children but must add the stress they face in dealing with professionals is unacceptable. No one seems clear with who does what."

- **<u>Cultural barrier</u>**
  - "Sometimes our biggest obstacle is helping families understand that they should not feel any shame in accessing York Region ASD services"

- **<u>Issues of supply and demand</u>**
  - "The York system seems to be doing significantly better than many, in terms of having a wide variety of supports in place and lots of information available to families and others. However, there are still significant limitations to access, primarily due to supply and demand - more people need more service than what is available."

- **<u>Considering the lifespan/adulthood</u>**
  - "Facilities and treatment programs must include purposeful adult lifestyle, social and physical programs and most especially the delivery of knowledge to parents/caregivers of individuals with ASD in understanding what needs to be done for their children to live well into adulthood on their own."