

Autism Spectrum Disorder Individualized Funding

Parent/Caregiver and Service Provider Surveys

Summary Report

Background

In 2016, the Government of Saskatchewan committed to implementing an Individualized Funding Program for parents and/or caregivers of children living with Autism Spectrum Disorder (ASD).



Individualized funding will provide parents with funding to purchase services that best suit their child’s individual needs. This will give parents the flexibility and freedom to choose from a range of interventions that they think will most benefit their child. This program supports the Saskatchewan Disability Strategy which is a 10-year comprehensive Strategy that sets out the vision to make Saskatchewan a more welcoming, inclusive, and accessible province for people who experience disability.

Consultation Approach

To ensure that the new Individualized Funding program responds to the needs of the children with ASD and their families/caregivers, it is critical to hear from parents/caregivers and service providers. The Autism Stakeholder Working Group developed two surveys – one for parents/caregivers of children with ASD, and one for service providers.

The surveys gathered information from parents/caregivers about the **service needs** of their children and information from service providers about **current private services offered** to help identify **potential gaps in service**. In addition, the surveys gathered input from parents/caregivers and service providers to help in the **design of an Autism Individualized Funding Program for Saskatchewan families**.

About the Autism Stakeholder Working Group

As part of the election commitment to implement an Individualized Funding program, an Autism Stakeholder Working Group has been brought together to provide recommendations to government on the Autism Individualized Funding Model.

Participants in the Working Group of 12-15 individuals have been chosen from across Saskatchewan to share their experiences raising a child with ASD, and/or providing services for families impacted by ASD.

Data Collection

Online Survey

Major stakeholder groups were notified about the survey by the program contacts in the Ministries of Health, Education and Social Services, and through the Autism Stakeholder Working Group, as soon as it was made publicly available on saskatchewan.ca. Groups were encouraged to share the links with those in their networks who could provide beneficial feedback. Paper surveys were provided as an option to respondents. Individuals could also express interest in participating in any additional consultation about individualized funding by providing their contact information. This survey was posted on Saskatchewan.ca from July 6th – July 26th, 2017.

ASD Community Stakeholders

In addition, stakeholder associations/organizations in the ASD community were sent a formal letter inviting them to provide written responses on behalf of their organization.

Other Interested People

Interested individuals other than parents/caregivers or service providers had the opportunity to provide feedback through a form on Saskatchewan.ca.

Response

244 parents/caregivers representing 290 children and 175 service providers completed the surveys. Two people that are neither parents/caregivers nor service providers also took the opportunity to submit personal comments via a feedback form on Saskatchewan.ca.

This document provides a summary of the results of the survey process.

We heard from:

**244 parents/caregivers
representing 290
children**

**175 service providers
cross Saskatchewan**

**More than 1,120 page
views on the public
consultation website**

Key themes



- Private services for children with ASD are very beneficial, but costly for parents/caregivers. Families are paying for private services primarily through self-funding but are frustrated that services are either not available or have limited availability where they live.



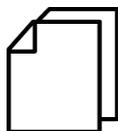
- Parents want to know more about services available through publicly funded programs as well as private services, including the potential benefits for their children.



- Both parents/caregivers and service providers identified regulated rehabilitation professionals and interventionists/aides/mentors as their top two priorities for services that should be eligible for individualized funding.



- For parents/caregivers to benefit from individualized funding there needs to be: increased capacity and service provider availability in their region; supports helping them navigate the system; and easily accessible information about what services are available and their potential benefit.



- Provision of funding needs to offer flexibility so parents/caregivers can choose services that are the most helpful, while balancing the administrative effort.

Summary

Service Needs

Most commonly accessed publicly-funded services included:

- health region services (82%)
- school divisions (76%)
- private service providers (52%)
- Early Childhood Intervention Program (ECIP) (44%)
- Child and Family Programs (41%)

The Community Living Services Delivery Family Program/Case Management, Cognitive Disability Strategy and respite (health region) are accessed by about one-quarter of respondents; another one-quarter of respondents are unsure if these services are beneficial. Saskatchewan Aids to Independent Living (SAIL) is the least accessed program (9%).

Private services that are used are generally self-funded. The most commonly accessed private services include:

1. Speech Language Pathologist (SLP) (56%)
2. Occupational Therapist (OT) (53%)
3. Psychologist or counselling (45%)
4. Applied Behavioural Analysis (ABA) (36%)
5. Respite care (31%)
6. Interventionist/aide/mentor to implement therapeutic programs (28%)
7. Physical Therapist (18%)

Private Services Offered

Based on the providers' responses, there are relatively fewer private service available to serve the populations in smaller cities, towns and rural areas compared to Regina and Saskatoon. For example, of 36 occupational therapists who responded, 20 offer service in Regina/Saskatoon while there are 16 providers available to serve all other geographic regions across Saskatchewan.

	Regina/ Saskatoon	Other	Total
Occupational Therapist (OT)	20	16	36
Speech Language Pathologist (SLP)	8	20	28
Applied Behavioural Analysis (ABA)	8	13	21
Therapeutic programs	3	15	18
Mentorship	3	9	12
Respite care	5	7	12
Physical therapist	3	5	8

Service Gaps: Publicly Available Services

The most commonly used public services for ASD are health regions and school divisions. Use is comparable between Regina/Saskatoon versus other communities.

Use of publicly-funded services for ABA, OT, SLP, PT was significantly higher for parents/caregivers living in Regina/Saskatoon compared to other communities. In addition, one-third of respondents indicated they have not accessed these types of publicly funded services because services are not available or have limited availability in their area.

Results also indicate opportunities to increase awareness of what public ASD services are available for families, as well as their potential benefits.

Service Gaps: Private Services

Similarly, use of private services through self funding is higher in Regina/Saskatoon compared to other Saskatchewan communities, for example 24% more parents/caregivers in Regina/Saskatoon used ABA and SLP compared other communities. One-third of parents/caregivers indicated they have not used private services through self-funding because it is not available or has limited availability where they live.

There are significant gaps between service needs of children with ASD and where service providers are located. For example, the private services most accessed with self-funding are SLP (30%) and OT (33%) and there are significant gaps in terms of availability between the larger centres of Regina and Saskatoon and other communities.

Parents/caregivers also voiced concerns about private services in terms of high cost (54% of comments) and availability of services (29%). Private services are beneficial (20%), but respondents also felt there needs to be more awareness of what is available (16%).

Design of an Autism Individualized Funding Program for Saskatchewan families

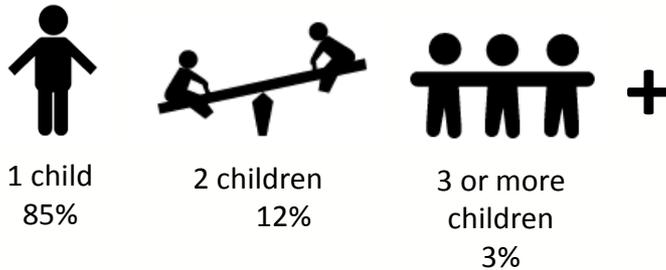
- Both parents/caregivers and service providers identified regulated rehabilitation professionals and interventionists/aides/mentors as their top two priorities for what should be eligible for individualized funding. Parents placed greater priority on applied behavioural analysis and psychology and counselling compared to service providers who placed greater priority on respite compared to the other two services. Therapeutic equipment and travel were lowest in terms of priorities.
- Activities/sports, other regulated service professionals, day/summer camps, educational assistance and parent supports and education were the top 5 “other” services mentioned by both groups.
- The preferred supports for parents and service provider respondents were a navigator and a listing of private service providers in the province. Parents identified an interactive website as a useful support. Service providers identified structured parent groups/networks and guidelines about evidence based interventions.
- In terms of preferences for how individualized funding is provided, parents/caregivers preferred receiving the amount annually, while service providers preferred a model where they invoice government. Both groups had low support for a payment card.

Detailed Results

Parent/Caregiver Results

About the families

How many children do you have that have been diagnosed with ASD, have shown signs of ASD, or are in process of being diagnosed with ASD?



What are their ages?

64% of children represented in the survey are between 6 and 17 years of age.



Describe your relationship to your child(ren)?



94% respondents are the biological parent/legal guardian.

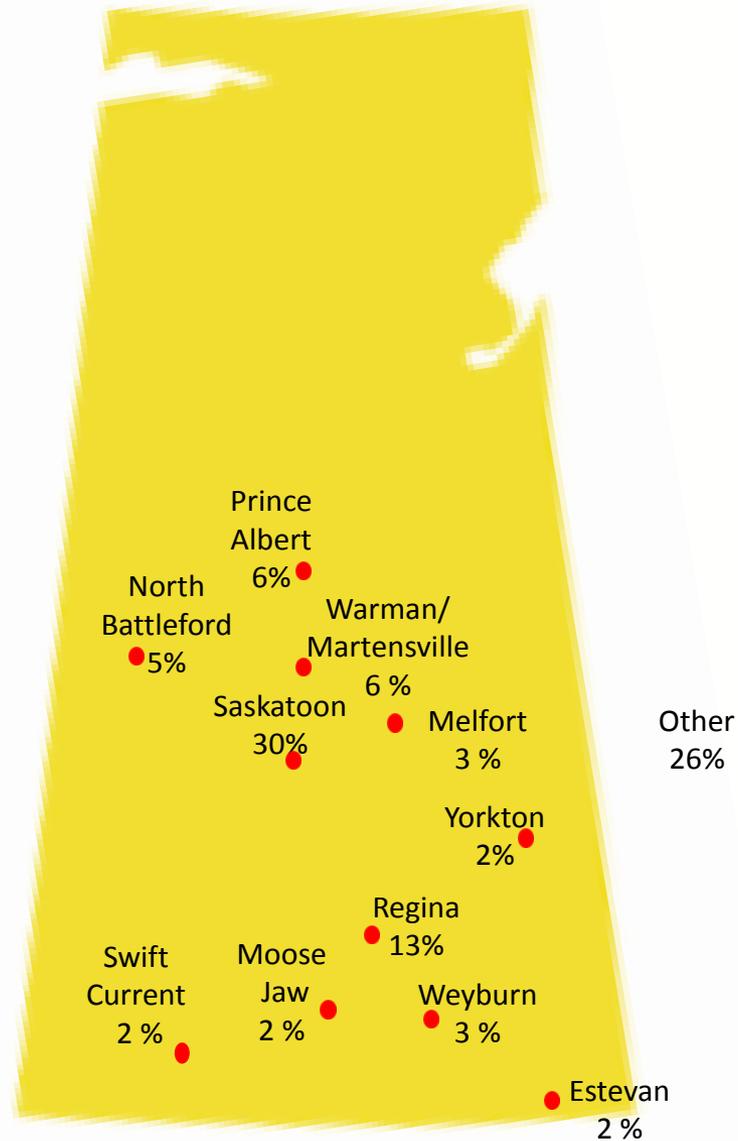
Has your child been diagnosed with ASD or shown signs of ASD/is in the process of being diagnosed



86% of children have been diagnosed with ASD.

Where do you live?

30% of respondents live in Saskatoon and 13% in Regina.



Have you accessed the following publicly-funded services for your child(ren)?

Most commonly accessed publicly-funded services included:

- health region services (82%)
- school divisions (76%)
- private service providers (52%)
- Early Childhood Intervention Program (ECIP) (44%)
- Child and Family Programs (41%)

One-third of respondents indicated they have not accessed a private service providers because **services are not available/has limited availability in their area.**

The Community Living Services Delivery Family Program/Case Management, Cognitive Disability Strategy and respite (provided by the health region) are accessed by about one-quarter of respondents; another one-quarter of respondents are **unsure if these services are beneficial to their child.**

Saskatchewan Aids to Independent Living (SAIL) is the least accessed program (9%). 63% of respondents indicated either this service is not applicable to their child or they are unsure if it would be of benefit to them.

Other mentions included: Autism Services of Saskatoon (5); mental health services, psychiatrist , psychologist (5); and interventionist/mentor (2). Detailed results on following page.

One out of every three parents/caregivers stated they had not accessed these funded services for applied behavioural analysis, occupational therapy, speech language pathology, physical therapy because the service is not available/has limited availability in their area.

Have you accessed the following publicly-funded services for your child(ren)?

	Yes	No, because the service is not available/has limited availability in my area	No, because my child is not eligible	Does not apply to my child	I'm unsure if service beneficial to my child
Health region autism program (ASD consultant or support worker, occupational therapist, speech language pathologist, physical therapist etc.)	82%	10%	4%	1%	2%
School division (e.g. Autism service provider, occupational therapist, speech language pathologist, psychologist, educational assistant, etc.)	76%	13%	7%	4%	1%
Private service provider (e.g. Applied behavioural analysis, occupational therapist, speech language pathologist, physical therapist etc.)	52%	31%	6%	4%	8%
Early childhood intervention program (ECIP)	44%	15%	15%	18%	8%
Community Living Services Delivery Family Program/Case Management	28%	18%	12%	19%	24%
Cognitive Disability Strategy (Flexible Funding, Cognitive Disability Consultant)	24%	19%	23%	10%	24%
Saskatchewan Aids to Independent Living (SAIL)	9%	15%	14%	31%	32%
Child and Family Programs	41%	22%	10%	5%	22%
Respite (Health region)	25%	19%	17%	17%	22%

Regina/Saskatoon versus All Other Communities

Have you accessed the following **publicly-funded services** for your child(ren)?

63% of parents/caregivers in Regina or Saskatoon have accessed private service providers for their child compared to 44% for all other communities.

	Regina/ Saskatoon	Other
Health region autism program (ASD consultant or support worker, occupational therapist, speech language pathologist, physical therapist etc.)	83%	82%
School division (e.g. Autism service provider, occupational therapist, speech language pathologist, psychologist, educational assistant, etc.)	74%	77%
Private service provider (e.g. Applied behavioural analysis, occupational therapist, speech language pathologist, physical therapist etc.)	63%	44%
Early childhood intervention program (ECIP)	33%	52%
Community Living Services Delivery Family Program/Case Management	21%	32%
Cognitive Disability Strategy (Flexible Funding, Cognitive Disability Consultant)	20%	27%
Saskatchewan Aids to Independent Living (SAIL)	6%	12%
Child and Family Programs	48%	35%
Respite (Health region)	11%	34%

Which of the following private services have you accessed for your child(ren)? All sources of funding

The most commonly accessed private services included

1. Speech language pathologist (SLP) (56%)
2. Occupational therapist (OT) (53%)
3. Psychologist or counselling (45%)
4. Applied behavioural analysis (ABA) (36%)
5. Respite care (31%)
6. Interventionist/aide/mentor to implement therapeutic programs (28%)
7. Physical therapist (18%)

Private services that are used are generally self-funded. Overall, one-third parents/caregivers indicated they have not used any of the private services listed because it is not available or has limited availability. Interventionists/ aides/mentors and applied behavioural analysis (ABA) are the services with the least availability at 40% and 37% (respectively).

Other mentions included:

- Equine therapy (5)
- Respite (3)
- Counselling (3)
- Sport/gym membership (3)
- Autism Services of Saskatoon (3)
- Naturopath (2)
- Music therapy (2)
- Educational assistants (2)
- Theraplay (2)
- Autism Awareness Centre (1)
- Irlen lenses (1)
- Biomedical (1)
- Audiologist (1)
- Little Tots (1)
- APD Treatment (1)
- Social skills group (1)
- Chiropractor (1)
- Private cognitive assessment (1)
- Weighted blanket (1)
- Family play therapy (1)
- Venture Academy (1)

One out of every three parents/caregivers stated they had not accessed privately available services for their child because the service is not available or has limited availability in their area.

Detailed results on following page.

Which of the following private services have you accessed for your child(ren)? How are they funded?

	Yes, mostly self-funded	Yes, mostly through Cognitive Disability Strategy Funding	Yes, mostly other funding sources	All Yes Responses	No, because the service is not available/has limited availability in my area	I'm unsure if service would be beneficial to my child
Applied behavioural analysis (ABA)	24%	4%	8%	36%	37%	27%
Occupational therapist (OT)	30%	7%	16%	53%	29%	19%
Speech language pathologist (SLP)	33%	7%	16%	56%	25%	19%
Physical therapist	6%	3%	9%	18%	26%	56%
Respite care	13%	7%	11%	31%	33%	35%
Psychologist or counselling	25%	5%	15%	45%	26%	30%
Interventionist/aide/mentor to implement therapeutic programs	12%	6%	10%	28%	40%	32%

Regina/Saskatoon versus All Other Communities

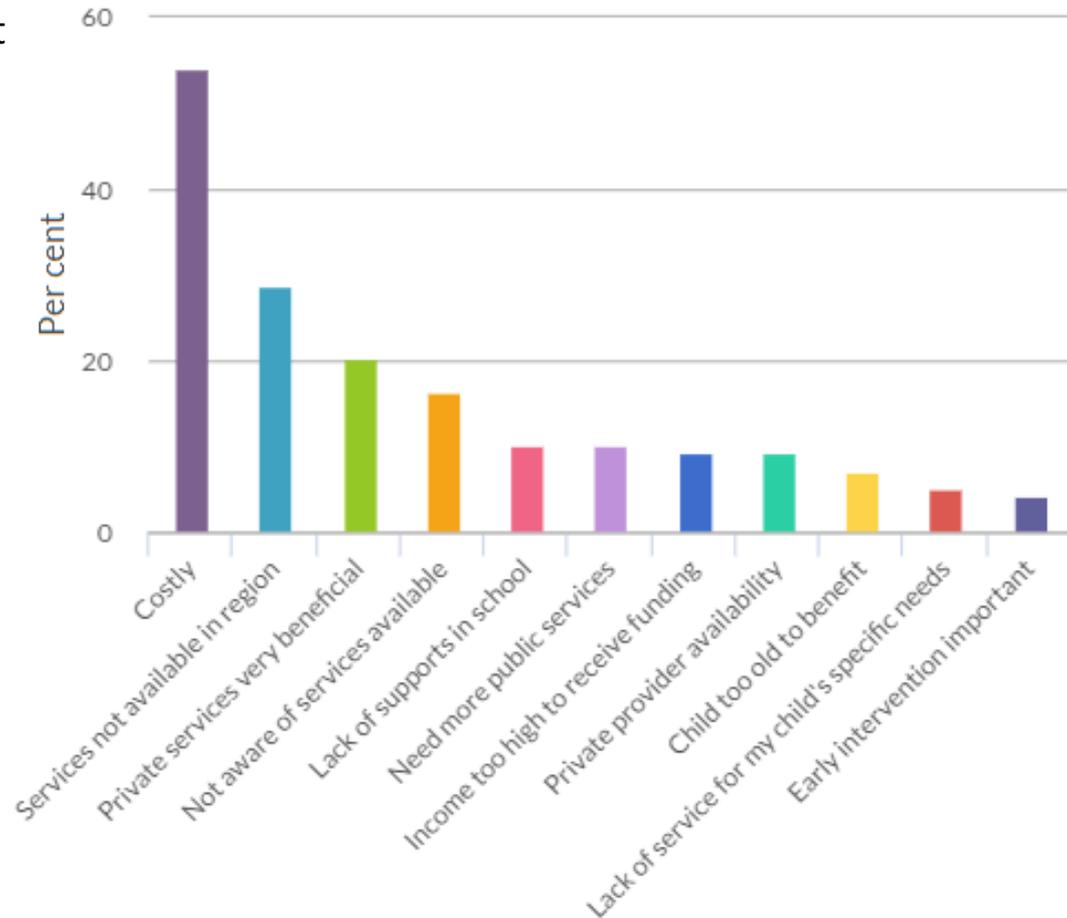
Which of the following private services have you accessed for your child(ren)? **Self-funded only.**

Use of private services using self-funding is higher in Regina/Saskatoon compared to other Saskatchewan communities, for example 24% more parents/caregivers in Regina/Saskatoon used ABA and SLP compared to other communities. Use of physical therapists and respite is comparable.

	Regina/ Saskatoon	Other
Applied behavioural analysis (ABA)	37%	13%
Occupational therapist (OT)	42%	22%
Speech language pathologist (SLP)	47%	23%
Physical therapist	7%	5%
Respite care	12%	14%
Psychologist or counselling	31%	18%
Interventionist/aide/mentor to implement therapeutic programs	19%	8%

Do you have any additional comments about private services?

Parent/caregiver concerns about private services focused on cost (54% of comments) and availability (29%) of services. Private services are beneficial (20%), but respondents also felt there needs to be more awareness of what is available (16%). Other frequently mentioned comments concern lack of supports in schools and need for more public services, both at 10% of comments.



How would you rank the following services in terms of what should be eligible for individualized funding? Rank them with the one most important to you as number 1.

- 1 Regulated rehabilitation professionals (e.g. Occupational therapists, speech language pathologist, physical therapists, etc.)
- 2 Interventionist/aide/mentor to implement therapeutic programs
- 3 Applied behavioural analysis
- 4 Psychologist or counselling
- 5 Respite care
- 6 Travel to access providers
- 7 Therapeutic equipment

What other services do you feel should be eligible for individualized funding? Top 12

Value	Percent	Responses
Activities/sports	26.2%	32
Regulated service professionals	20.5%	25
Day/summer camps	16.4%	20
Training for EAs/more EAs/tutoring	13.9%	17
Parent supports/education	13.1%	16
Pet/equine therapy	13.1%	16
Supportive living workers/group home	12.3%	15
Special diets/supplements	11.5%	14
Therapeutic equipment	9.0%	11
Naturopath	8.2%	10
Respite care	7.4%	9
Medical expenses	7.4%	9

What do you perceive could be barriers to parents/caregivers to using individualized funding for services?

The most significant barriers for parents/caregivers:

1. “limited services providers where they live” (84%)
2. “unsure of what private services are available in their area” (75%) and
3. “service providers are too far away” (73)%

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not applicable/ Don't know	Agree + Strongly Agree
Unsure what their child needs	15%	12%	9%	35%	27%	2%	62%
Unsure of what services are evidence based	8%	11%	16%	36%	24%	5%	60%
Unsure what private services are available to them in their area	6%	8%	10%	31%	44%	1%	75%
Limited service providers where they live	3%	3%	8%	23%	61%	2%	84%
Service providers too far away	6%	5%	15%	26%	47%	3%	73%

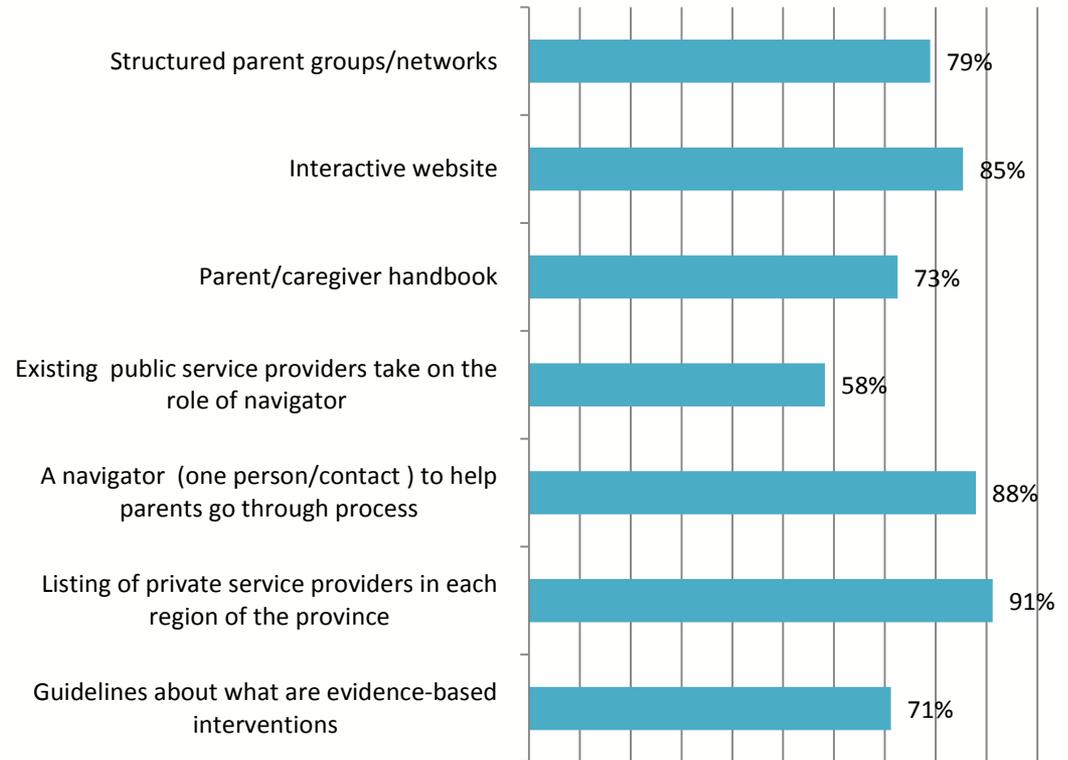
Other (# of mentions):

<i>Funding</i>	(10)
<i>Not enough information about services</i>	(10)
<i>Lack of services available</i>	(6)
<i>Navigation</i>	(6)
<i>Wait lists</i>	(6)
<i>Services needed not covered</i>	(5)
<i>Time off work</i>	(5)
<i>Cash flow</i>	(4)
<i>Diagnosis</i>	(4)
<i>Travel</i>	(4)
<i>Child care other children</i>	(3)
<i>Income</i>	(3)
<i>Not eligible for funding</i>	(3)
<i>Paperwork</i>	(3)

To what degree do you feel the following potential supports would assist you in accessing the services you need? (Agree + Strongly Agree)

The most popular supports among parent/caregiver respondents were:

1. listing of private service providers in each region of the province (91%)
2. a navigator (one person/contact to help parents go through process (88%), and an
3. interactive website (85%)

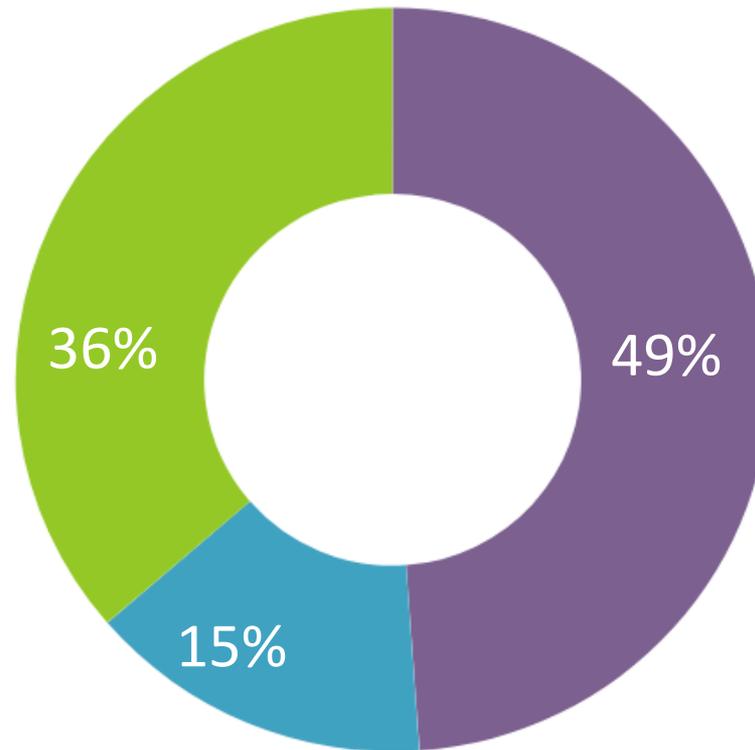


What would be the most convenient option for providing parents with individualized funding?

An annual amount for parents to manage was the preferred option for providing individualized funding at 49% of responses followed by service provider submits invoices to government at 36%.

Payment card was the least popular choice at 15%.

In addition, 8 respondents suggested funds be provided monthly.

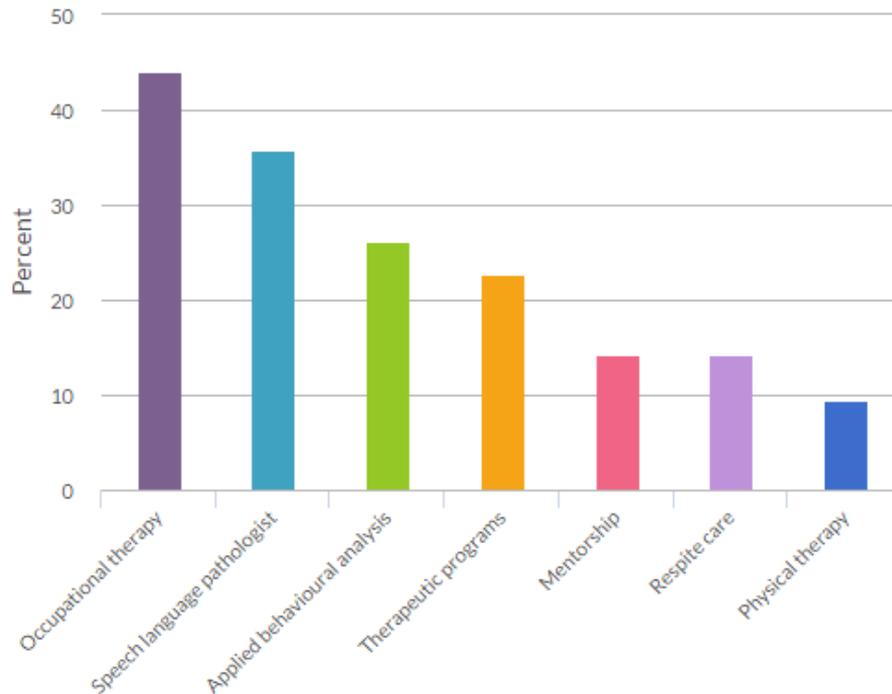


- Annual amount provided to parents/caregivers to manage
- Payment card (e.g. preloaded purchase card)
- Service provider submits invoice to government for payment

Service Provider Results

About the service providers

Of the service providers that responded to the survey, 44% provide OT, 36% offer SLP, 26% provide ABA, and 23% provide therapeutic programs.

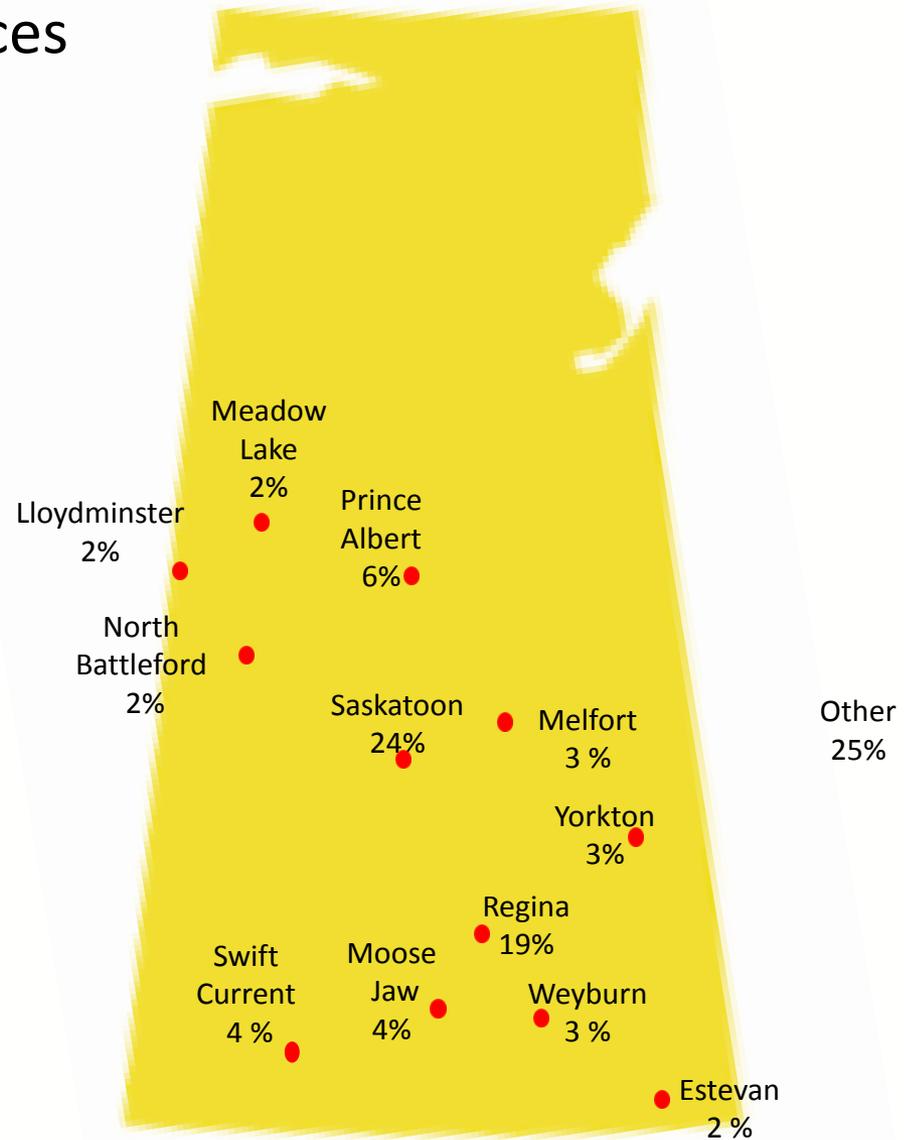


Other comments (# of mentions):

<i>Support worker</i>	(17)
<i>Early childcare education/childcare</i>	(15)
<i>Services coordinator</i>	(15)
<i>Diagnosis/assessment/consultation</i>	(14)
<i>Psychologist/counselling</i>	(11)
<i>Parent groups/coaching</i>	(11)
<i>Social skills/inclusion</i>	(11)
<i>Education</i>	(10)
<i>Recreation program</i>	(9)
<i>Residential program</i>	(8)
<i>Intervention/David Lloyst</i>	(7)

Where do you offer services for children with ASD?

24% of respondents offer services in Saskatoon and 19% in Regina.



Services Provided – Regina/Saskatoon versus Other

Based on the providers' responses, there are relatively fewer private service available to serve the populations in smaller cities, towns and rural areas compared to Regina and Saskatoon. For example, of 36 occupational therapists who responded, 20 offer service in Regina/Saskatoon while there are 16 providers available to serve all other geographic regions across Saskatchewan.

	Regina/ Saskatoon	Other	Total
Occupational therapist (OT)	20	16	36
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Applied Behavioural Analysis (ABA)	8	13	21
Therapeutic programs	3	15	18
Mentorship	3	9	12
Respite care	5	7	12
Physical therapist	3	5	8

How would you rank the following services in terms of what should be eligible for individualized funding? Rank them with the one most important to you as number 1.

- 1 Regulated rehabilitation professionals (e.g. Occupational therapists, speech language pathologist, physical therapists, etc.)
- 2 Interventionist/aide/mentor to implement therapeutic programs
- 3 Respite care
- 4 Psychologist or counselling
- 5 Applied behavioural analysis
- 6 Therapeutic equipment
- 7 Travel to access providers

What other services do you feel should be eligible for individualized funding? Top 12

Value		Percent	Responses
Parent supports/education		25.0%	20
Activities/sports		23.8%	19
Regulated service professionals		16.3%	13
Day/summer camps		13.8%	11
EAs		12.5%	10
Social skills		11.3%	9
Childcare		10.0%	8
Supports for older children/young adults		10.0%	8
Pet/equine therapy		8.8%	7
Music therapy		8.8%	7
Therapeutic equipment		7.5%	6
Group therapy		7.5%	6

What do you perceive could be barriers to parents/caregivers to using individualized funding for services?

Service providers thought the most significant barriers for parents/caregivers would be:

1. “limited services providers where they live” (94%),
2. “service providers too far away” (85)%
3. “unsure of what private services are available in their area” (81%)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not applicable/ Don't know	Agree + Strongly Agree
Unsure what their child needs	5%	10%	5%	39%	41%	1%	80%
Unsure of what services are evidence based	1%	6%	12%	25%	52%	4%	77%
Unsure what private services are available to them in their area	1%	5%	12%	37%	44%	1%	81%
Limited service providers where they live	1%	1%	4%	20%	74%	1%	94%
Service providers too far away	2%	1%	12%	25%	60%	1%	85%

Other comments (# of mentions):

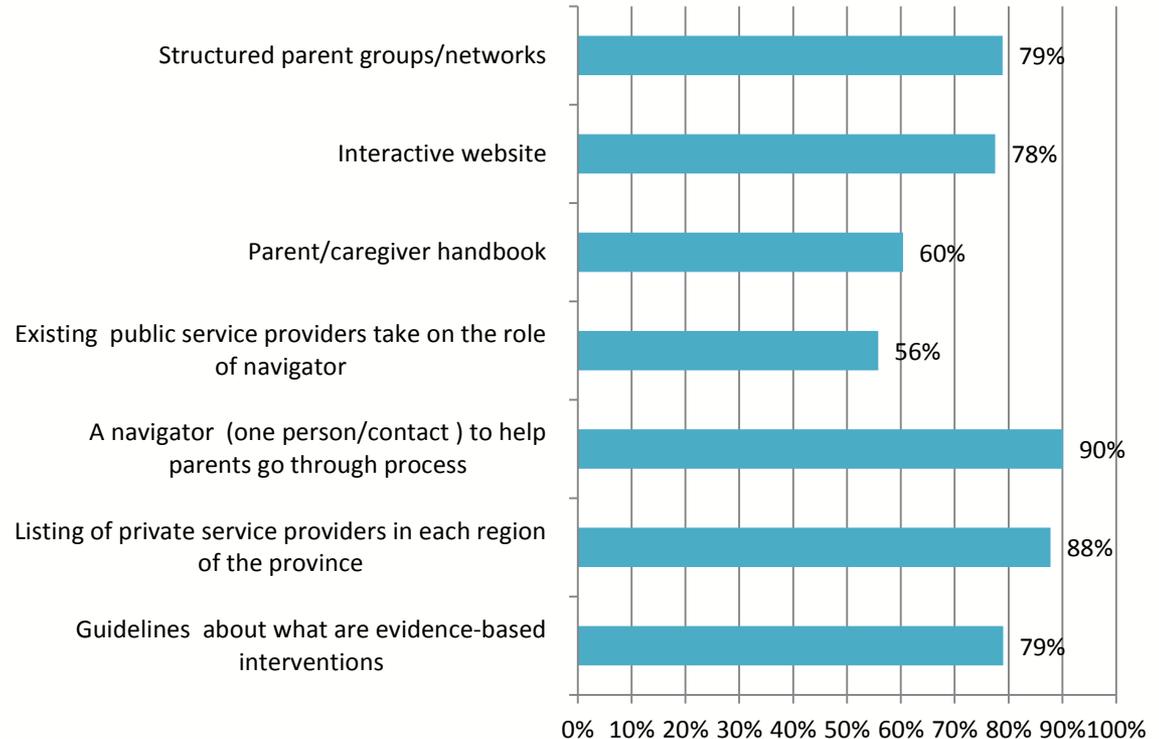
- Complexity of process (15)*
- Lack of services available (13)*
- Case management (10)*
- Need information about services (6)*
- Paperwork (6)*
- Travel (6)*
- Diagnosis (5)*
- Funding (5)*
- Need professional collaboration (4)*
- Parental exhaustion (3)*

To what degree do you feel the following potential supports would assist parents in accessing the services they need? (Agree + Strongly Agree)

The most popular supports among service provider respondents were:

- Navigator (one person/contact to help parents go through process (90%),
- Listing of private service providers in each region of the province (88%)
- Structured parent groups/networks and guidelines about evidence based interventions (both at 79%)

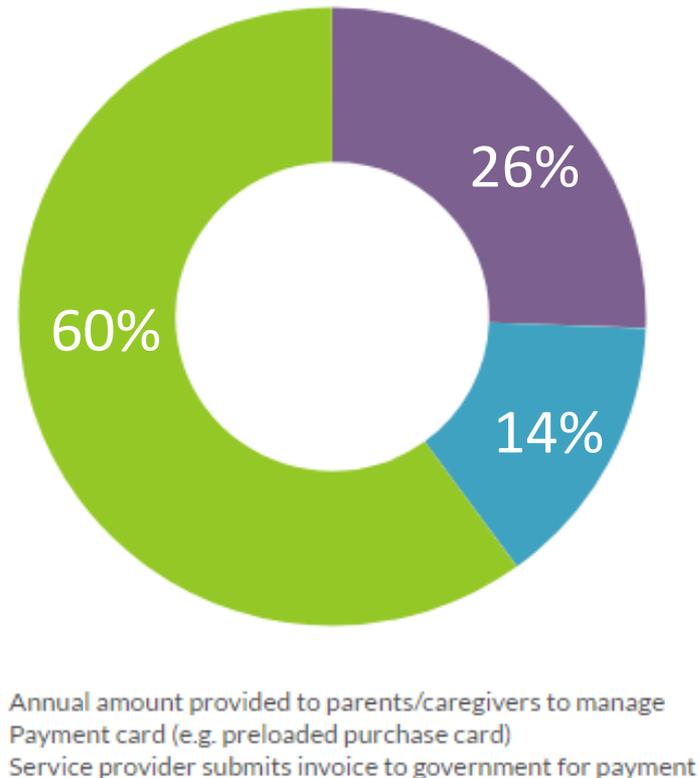
Other suggestions from service providers included a hotline for emergencies or information on service providers; a focus on having more service providers in smaller communities, and greater collaboration across professional groups and agencies, including schools.



What would the most convenient option for providing parents with individualized funding be?

Service provider submits invoice to government was the preferred option to provide parents with individualized funding at 60%, followed by annual amount provided to parents/caregivers (26%).

Payment card was the least popular choice at 14%.



More on payment

More frequent payments (monthly or quarterly) was suggested by a few service providers. They identified that purchase cards may be a barrier for parents in Northern Communities.

Service providers also identified that most parents are able to look after funds; however, they noted some families do require assistance with this. A navigator could help them set up how to budget for annual services.

Another sentiment was that an annual amount would be most convenient, but families still need to be accountable on how they use the funds. This could be addressed by parents being required to submit paperwork to the government or invoices provided by the provider to ensure funds are being used appropriately.

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