



*Exo questionnaire*

# You and your community

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# Introduction

The following statements are about how having a child who is at risk for developmental delays may have affected you and your family as a whole. Through our numerous conversations with parents of children with special needs, these issues often came across as areas of great concern. By filling out this portion of the questionnaire you will be giving those who work with children who are at risk for developmental delays invaluable input as to what would be some of the challenges that face parents of children who are at risk for developmental delays. What we are looking for, specifically, is information about the barriers to the social inclusion of at risk children, from your perspective as a parent. Often times it has come to our attention that children who are at risk for developmental delays are excluded from certain neighborhood programs or schools. We would like to identify some of the reasons behind this exclusion so that the barriers can eventually be addressed and removed. This, in turn, will help us strive to provide you and your family with better services (services that address your family's needs as a whole).

Please note that these questionnaires are completely anonymous. However, by getting the first three digits of your postal code we could try to determine where some of the difficulties you are experiencing might be coming from.



*Section A*

# Support-Related Stressors

The following statements are about your everyday experiences with the professionals who work with your child. Please indicate whether or not you agree with the following statements by checking one of the boxes:



**Q: I feel frustrated/stressed by:**

1. Not knowing what services are available for my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

2. Not knowing where to go for services

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

3. Not knowing where to go for extra funding or financial support

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

4. Not having enough specialized services for my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

5. Not having licensed and/or certified professionals working with my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

6. The lack of centralized services (i.e. having to go to different places for different

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

7. The lack of continuity of services (e.g. having to change service providers because my child has reached a certain age)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

8. The lack of coordination of services between different service providers

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

9. Not being able to send my child to a neighborhood program (because the time of the program is not appropriate and/or because available programs do not accommodate children who are different)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable



**Q: I feel frustrated/stressed by:**

**10.** Sometimes getting the same service from more than one agency while not getting another service altogether (e.g. getting advice on how to improve my child's motor skills from more than one consultant/therapist and not getting any advice on how to help my child develop his/her language skills from any consultant/therapist)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**11.** Sometimes getting contradictory information from different service providers (e.g. regarding how to help my child with his/her communication skills)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**12.** Having to wait a long time for services to start

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**13.** Having to transition my child from one setting to the next without much help from service providers

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**14.** Availability of services in "cycle" modes only (e.g. having speech therapy services in three month cycles, where my child would get the therapy for three months, then it would stop for three months, then it would start again for three months...)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**15.** Too much intervention/too many specialists working with my child

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**16.** Too little intervention/too few specialists working with my child

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**17.** Having too little testing done on my child

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**18.** Having too much testing done on my child

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable





*Section B*

# Satisfaction with Agencies

The following statements are about any agency (agencies) you have to deal with and your overall satisfaction with this agency (these agencies).

Please indicate whether or not you agree with the following statements by checking the appropriate box:



**Q: I am frustrated with the inability/unwillingness of my child's school or day care center or preschool or community agency or home based program to:**

**19. Provide transition services from one setting to the next (e.g. transition from preschool to kindergarten)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**20. Provide appropriate academic services (provide instruction in a way that is appropriate to my child's learning style)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**21. Have qualified personnel to deal with my child (i.e. personnel with the right training and experience to deal with a child who has the special needs that my child has)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**22. Provide my child with assessment services (e.g. assessment to learn how my child learns best)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**23. Develop a classroom behavior management plan for my child (e.g. a plan that would give teachers and aides ideas about what to do, should my child throw a tantrum in class)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**24. Provide ongoing support to manage my child's condition (e.g. the school /centre has an IEP in place, but no support to apply and maintain what is in the IEP)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**25. Give my child his/her medication (e.g. for epilepsy, ADHD or asthma)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**26. Give me advice on how to manage my child's behavior at home (so there would be some consistency between what happens at school and what happens at home)**

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable



**Q:** I am frustrated with the inability/unwillingness of my child's school or day care center or preschool or community agency or home based program to:

**27.** Give me advice on how to help my child with his/her homework (what strategies seem to work best with children who have special needs)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**28.** Refer me to appropriate professionals in the community (e.g. behavior consultants, speech and language pathologists, psychologists...)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**29.** Explain things to me in a way that I can understand (instead of using too many technical terms)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**30.** Make me an equal partner in any decision that is to be taken about my child

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**31.** Be available when I have questions

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable





## *Section C* Satisfaction with Services

In the following section, there are more questions regarding your satisfaction with the services provided to your child and those who provide those services.

Please indicate whether or not you agree with each of the following statements by checking the appropriate box:



**Q:** I feel that:

**32.** It is easy to connect with services in my community (e.g. easy to access professionals who can help my child)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**33.** It is easy to find services in my community (such as the Infant Development Program of British Columbia or Public Health agencies)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**34.** I have not been given enough information to be able to care for my child at home (e.g. what to do if my child has a seizure or a temper tantrum)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**35.** I am being pulled in different directions by different service providers

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**36.** The services my child is receiving are based on my child and my family's needs

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**37.** The service providers I work with are sensitive to my family's cultural/racial/ethnic background

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**38.** Service providers and school personnel should be better educated about my child's condition (e.g. I sometimes feel that the people who work with my child do not really know him/her)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**39.** My child's school/preschool/day care center/community agency does not do enough to prevent attitudinal barriers to my child's social inclusion in different activities (e.g. some personnel may look the other way when my child gets teased or gets excluded from certain activities)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable



**Q:** I feel that:

**40.** Some teachers/community workers can be quite rude to my child because he/she is different (e.g. they may avoid him/her or be less patient with him/her than they other with other children)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**41.** My child often gets ignored by the school/preschool/day care center/community agency personnel

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**42.** The mission statement of my child's school/preschool/day care center/community agency does not include acceptance of those who are different (e.g. there is nothing in the statement about accepting and respecting all those who may be different)

☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable



*Section D*

# Hearing of Agencies and Services in your Neighbourhood

The following is a list of services and agencies that are available in your neighborhood and elsewhere. Please indicate whether or not you have heard of these services and/or agencies by checking the appropriate box:



**Q: I have heard about :**

**43. Financial support services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**44. Internet resources**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**45. Mental health services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**46. Occupational therapy services (including sensory integration)**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**47. On-line child development and/or atypical development courses**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**48. Physical therapy services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**49. Professional psychology and/or diagnostic services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**50. Speech therapy services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**51. The Hanen program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**52. The Infant Development Program of British Columbia**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**53. The Parent Child Mother Goose program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**54. The services provided by the ministry of child and family development**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**55. The services provided by the ministry of education services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**56. The services provided by the ministry of health services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**57. The supported child development program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable





*Section E*

# Knowledge of Agencies and Services in your Neighbourhood

It is possible that you have heard of the above mentioned services and/or agencies but do not really know about them. In the following section, please indicate whether or not you really know these services and/or agencies, by checking the appropriate boxes:



**Q: I have knowledge about:**

**58. Behavior therapy services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**59. Financial support services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**60. Internet resources**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**61. Mental health services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**62. Occupational therapy services (including sensory integration)**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**63. On-line child development and/or atypical development courses**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**64. Physical therapy services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**65. Professional psychology and/or diagnostic services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**66. Speech therapy services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**67. The Hanen program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**68. The Infant Development Program of British Columbia**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**69. The Parent Child Mother Goose program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**70. The services provided by the ministry of child and family development**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**71. The services provided by the ministry of education services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**72. The services provided by the ministry of health services**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable

**73. The supported child development program**

☐ Yes ☐ Not ☐ Not sure ☐ Not applicable



*Section F*

# What would make your Life Easier?

The following statements are about services that might help make your life easier. Please indicate whether or not you would like to have any of them:



**Q: I would like to:**

**74.** Have one person who would be my primary contact and/or advocate for all services offered to my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**75.** Meet more often with the professionals who are working with my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**76.** Feel like an equal partner in the education and/or therapy treatments of my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**77.** Feel like an equal partner in the intervention program of my child

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**78.** See professionals monitor (i.e. follow up on) the goals they have set for my child more often than they currently do

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**79.** See professionals report assessment results to me in a way that I can understand

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**80.** Know more about my child's rights when it comes to assessment issues (e.g. what he/she is entitled to in terms of testing)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**81.** Know more about my child's rights when it comes to intervention issues (e.g. what he/she is entitled to)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**82.** Know more about my child's rights when it comes to schooling issues (e.g. what he/she is entitled to in terms of therapies, treatment, programs)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable



**Q:** I would like to:

**83.** Have some brochures in my first language (e.g. child development or early intervention services brochures)

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**84.** Participate in parent panels that would help raise awareness about the needs of children who are at risk for developmental delays

- ☐ Yes      ☐ Not      ☐ Not sure      ☐ Not applicable

**85.** Please enter your City/Town:

**86.** Please enter your Province/State

**87.** Please enter the first 3 letters of your Postal Code: