

**ENABLING PARENT ACCESS TO INFORMATION:  
DEVELOPING A DATABASE OF DISABILITY SUPPORTS  
FOR CUPW/UPCE-PSAC MEMBERS**

**REPORT ON THE INVESTIGATIVE PHASE**

## EXECUTIVE SUMMARY

### Project summary

CUPW proposes to improve parent access to disability information by developing a database of disability specific resources, programs and services<sup>1</sup>. In order to determine the viability of a database project, CUPW conducted an Investigative Phase to examine the current state of lists and databases of disability supports across Canada and to learn about the disability support information needs of members in the Special Needs and Moving On Projects.

### Background

For several years the two national projects of the CUPW Child Care Fund, the Special Needs and Moving On Projects, have recognized the need for improved parent access to information about the disability supports their child(ren) and family require. To meet this need, the Projects envision an online searchable database of current disability supports for CUPW members who have children or adult sons and daughters with disabilities: the CUPW disability supports database.

The work on the CUPW disability supports database begins with this Investigative Phase. The purpose of this phase is to:

- Discover what work is being done across the country related to lists/databases of disability support, to avoid duplicating the efforts of others and to engage potential partners
- Learn about the disability support needs and experiences of parent members who are currently part of the Special Needs and Moving On Projects
- Propose the next steps for the CUPW disability supports database.

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<sup>1</sup> From this point on, 'disability supports' will be used to refer collectively to disability resources, programs and services.

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- CUPW identified key features of a proposed database of disability supports to guide this work: an online searchable database available beyond members that includes disability resources, programs and services; encompasses provincial, territorial and national information; supports a range of special needs/disabilities across the lifespan, is regularly maintained and provides telephone support to members.

## Process

Internet searches, online navigation and key informant interviews were the methods used to discover and gather information about current lists and databases of disability supports nationally, provincially and in the territories.

A Parent Survey was developed to learn about the disability support and information needs of parent members. Survey questions addressed the disability supports parents are using now, would like to use and their overall experience finding the supports they needed. All parents in the Special Needs and Moving On Projects were able to complete this survey during the regularly scheduled 2015 fall telephone interview with Project Advisors.

## Key Findings

### Lists and databases of disability support information

There is an enormous amount of information about disability supports in the provinces, territories and nationally. Government departments and ministries, disability organizations and community information services/organizations across the country provide listings and databases of disability resources, programs and services. These lists/databases have different scopes and mandates and differ in how they are organized, populated and maintained. While several databases exist that have a national scope, these databases are specific to a particular disability, client group or program/resource area.

There is no one national database of disability resources, programs and services that meets the key features identified by CUPW.

There is, however, a growing network of 211 community information services in the provinces and territories. 211 services provide online searchable database and telephone support information about community social, health and government services, including disability supports. 211 services are standards-based and have an open data philosophy, making data as open and available as possible to the community through the creation of partnerships and portals of 211 data.

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There are North American recognized standards of information and referral organizations. Inform Canada is the national organization that supports best practices in the information and referral sector through these standards and certifies information/referral staff in Canada. Key areas of the standards are the classification/organization system, staff training and certification and database maintenance.

### Parent support and information needs

Through the Parent Survey, CUPW member parents shared their child's age and diagnosis, the disability supports they are using now, those they would like to use and their overall experience finding the supports they need. Parents also provided comments on the proposed CUPW disability supports database.

In both CUPW projects, there are identified disability support needs according to the child/adult son or daughter's age, diagnosis, what supports parents want to get and keep and overall priority supports.

Parents in both projects have difficulty finding disability supports due to lack of time and information, and when they have children/adult sons & daughters of certain ages, certain diagnosis and multiple diagnoses. Parents identified certain disability supports that lack information.

Parents want current information about disability supports and they want information about the disability supports that are close to home.

Many parents would easily use a disability supports database, especially if the database had a user-friendly layout and easy navigation. There are some members who are not comfortable using computers and/or mobile devices.

### Conclusions

The findings from the Investigative Phase lead to these three conclusions for CUPW disability supports database:

1. There is no need for CUPW to start anew building a national online database of disability supports.
2. A CUPW online database of disability supports can be built through partnership with the organizations in the provinces/territories that have existing community and human services information databases. The 211 network is the partner of choice for this work as identified through this Investigative Phase.

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3. Additional resources will be required for those parents needing individual assistance with disability support information due to more complex child and family situations, time constraints and lack of comfort or skill with computers. A Support Navigator resource person can address these and other member needs related to disability support information.

**Recommendations for next steps**

The findings and conclusions show the way to a plan to enable parent access to disability support information through partnership with the 211 network and a Support Navigator resource person.

It is recommended that a pilot project begin the work of the CUPW disability supports database. The pilot project will begin building the disability supports database from the 211 Ontario and 211 Nova Scotia data sets. Both Ontario and Nova Scotia have 211 services throughout their provinces; Ontario has the largest number of members in the Special Needs and Moving On Projects. A part time Support Navigator resource person will be added to the Special Needs/Moving On Projects team.

The pilot CUPW/211 disability supports database will be accessible from and embedded in both the Special Needs and Moving On Projects website, and the 211 Ontario and 211 Nova Scotia sites.

A Working Group of CUPW staff, 211 leads from Ontario and Nova Scotia, parents and Advisors from the CUPW projects will guide the pilot project and gather feedback to assess and evaluate the pilot prior to expanding the development process to other provinces/territories.

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