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Submission by: **The Community Living Coalition**

To: Refocus Working Group

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On the Refocus of Supported Child Care

**A Discussion Paper: CHILD DEVELOPMENT:
Strengthening the Infant Development/Child Development Continuum**

The **Community Living Coalition (CLC)** is an open and inclusive gathering of people and organizations dedicated to empowering individuals and families to make decisions about how they lead their lives in community. To achieve this vision, the coalition is moving forward with the provincial government to develop a new governance structure for community living services for children with special needs and adults with developmental disabilities. Members include: family members, self advocates, community agencies and partners, and friends of community living.

The CLC is very interested in the refocus of Supported Child Care. Having read and discussed the discussion paper it was decided that the coalition would like to provide our thoughts and feedback to the process.

We would like to acknowledge and appreciate that a great deal of effort, thinking and discussion has been involved in the evolution of the discussion paper. We appreciate the efforts undertaken have also ensured a positive outcome to what originally was a very concerning financial picture. We also appreciate that the direction to the refocus of supported child care has been from a spirit and desire to better meet the unique needs of children with extra support needs and their families, and also to create more flexibility within this program.

We acknowledge that the language and positions within the discussion paper recognizes the importance of early childhood development. However, we believe it should present an equally strong focus on support to the family. We believe that the needs of the child cannot be separated from the needs of the family.

Of equal importance is the necessity to address issues for school age children and the unique considerations of teens. For working parents, and their children, having access to quality child care support and inclusive environments to learn, grow and **interact with**

peers is critical to their development and well-being. Supports for families who face the extra ordinary challenges of parenting a child with special needs is fundamental to family and child well being, and to healthy communities.

Direct Funding Options, while not a choice for all families, is an important element in this paper. Along with the suggested introduction of direct funding we are glad to see recognition included for the need to provide support and assistance to families, such as administrative support, as an important consideration in assisting families who may request this support. Introducing direct funding certainly increases flexible options to families however what this will amount to is very vague. If it means that families will be required to make significant financial contributions to the costs of support staff required to ensure their children have access to quality child care then we have grave concerns for the real impact faced by families. Parents are willing to pay typical costs that all other families pay however it is unfair to expect them to cover the additional expenses that are required to provide access to developmental and community opportunities and options, especially when staffing support is required. This becomes an even greater concern for families with teens and an expense that other families do not face.

Overall impressions:

The focus on Child Development and the stated priorities for children birth to 6 years of age is a very important direction but of equal importance is the issue of childcare for families who are working or going to school/training. We feel that child development and childcare cannot be separated. A focus that is solely on child development negates the issues for working families, a reality that impacts a large percentage of families now a day. The priority for many families is for access to quality supported childcare including out of school care options in order to have equal access to the labor force.

We strongly believe that equal priority must be given to childcare for school aged children, both 6 to 12 year olds and 13 to 18 year old teens.

Of specific concern is the lack of commitment to teens.

For youth who require support they also face the challenge of very limited access to any inclusive community environments that their typical peers attend. The reality is that any teens that would require out of school support and assistance are youth with disabilities who have health and safety concerns and also significant extra support needs. They will typically require a full continuum of support life long. These are youth who are not in a position to be able to go out in community on their own, connect with peers, volunteer and hold part time jobs independently like their peers. Families who are in the work force and have teens that requires out of school support, are in a very different position than families with typical teens.

We feel strongly that the position of approval for support for children **over 12 must not be decided or viewed as an “exception to policy”**. We believe that if there is a request for support for teens to have access to “youth care” for out of school hours – especially if it is due to parents working, that the very request is evidence of need.

The discussion paper refers to a “comprehensive basket of services”, and we believe it is an essential need for families who are caring for teenage sons and daughters with disabilities, that they have access to a comprehensive basket of services life long. The available support services for teens with disabilities continues to be an under resourced area of service in most communities and has not received the focus due. When parents are continuing their commitment to their children throughout their teen years, a life period where increased challenges and stressors present, then it is in the teens, families and, communities best interest to support them.

It is well recognized that when families and their children are well supported in the teen years, the family will be better equipped to support their sons and daughters through their adult years, and all involved will experience healthier outcomes.

As well, we are concerned about a possible direction where teens and their families are being served under a model that’s focus and priority is early childhood development. We believe that the skill set for supporting children in the earlier years are very different than the teen years and therefore requires specific considerations and focus.

This age group requires **specific support and experience** with:

- an understanding and background of children and families at this age/life stage
- an understanding of the typical teen culture
- support that has connections to community links and options from a teen perspective and interest
- skills in facilitating connections and relationship building between typical teens and teens with disabilities
- a different focus on supporting teens with challenging behavior
- skills to provided dignified support personal care
- an understanding on adolescent/teen development and supporting healthy sexuality
- knowledge, skills, and resources to assist in the major transition issues that occur in the teen years and from these years onto young adulthood
- skilled support workers. For many teens requiring support it is because of complex and often challenging needs, that exceed the ability or even responsibility that could be expected of volunteers

Summary:

We are in full support of a refocus and improvement of supports for children to have access to early childhood development opportunities. Having increased flexibility and access to support in inclusive community environments is excellent. All children deserve the right to grow to the best of their abilities, and where needed, with the supports provided.

However we have **significant concerns**.

- the diminished prioritizing of commitment to **school age children**. In refocusing and improving the supports we provide to children, youth and families this would have been an ideal time to reconfirm and provide a commitment to teens and their families, moving beyond a position of only providing supports on an exemption to policy bases. This would mean recognizing needs versus continuing to hold an exception to policy position that is an unfair message to families and to their teens.
- **how many more children can be served, and waitlists reduced**. If it is as a result of diminished services, that place financial burdens on families, then we are not in support. We are also not in support of a position that would put the majority of supports to children only through the early years.
- **lack of commitment to youth and their families**
- weakened position of critical support to **families who are working** – “labor force attachment”. The challenges faced by families to access paid employment and to find quality childcare for their children with extra support needs is recognized Nationally and said to be a priority focus for Canadian families.
- Stable continuum of service throughout childhood and how to best meet a child’s needs is critical but cannot be seen separate and apart from how to best **meet the needs of the family**. When families feel strong and healthy, and receive the necessary support to meet the extra ordinary challenges in parenting a child with special needs/disabilities, then they better equipped to ensure the needs of their child are met.

Recommendation:

In that the discussion paper demonstrates a focus and priority for younger children, and in that we are concerned for equal access for school age children, and especially teens, we recommend that the **responsibility and associated supports/resources that currently serve children/youth 13 to 19 and their families be moved to the Community Living Authority along with the other children and youth Community Living Services**.

The philosophy of community living recognizes that children and youth with disabilities may require a life long continuum of planning and support. The introduction of direct funding could be utilized under a “basket of services” offering a continuum of support through and to the adult years. It may fit well within a model where families would be able to submit a support plan to address the holistic needs of the family and teen.

Conclusion:

Over the last 2 decades we have come a long way in supporting families and their children and youth with special needs, especially in relation to developmental opportunities as well as inclusive childcare practices and options.

But what must also be remembered is that we have in some ways reduced support to families and have asked them to take on larger levels of responsibility for these services.

The contribution that most families make to their sons and daughters, throughout their lifetime is significant. Their commitment is unending. To move forward in any direction that places increased demands, diminished core supports, or increased financial burdens on families will be taking us in the wrong direction. In that our aim is to provide the best supports to assist with healthy development and positive outcomes for both the child and the family, we must acknowledge the extra ordinary challenges faced by families and ensure support is available that both meets the needs of the child and the family.

Respectfully submitted by,

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On behalf of The Community Living Coalition

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