



Session summary and what was shared:

Individualized Funding for families with Children and Youth with Support Needs

About the Symposium Speakers' Series

As part of the Children and Youth with Support Needs (CYSN) engagement, a virtual speaker series was held to connect professionals in the field of child and youth development and disability with British Columbians. The series was also an opportunity to participate in a facilitated dialogue to help inform a new provincial CYSN service approach that is balanced with local situations and individual needs.

This virtual symposium speaker series was open to all British Columbians and provided a unique opportunity to foster collaboration and sharing among families, professionals, service providers, and interested parties. The breakout room discussions provided participants with an opportunity to engage in inclusive conversations, share insights, best practices, and explore research and session learnings through an anti-racism lens.

Session Overview

On Tuesday, November 30, 2023, Dr. Rachele Hole and Dr. Tim Stainton presented on "Individualized Funding for Families with Children and Youth with Support Needs." Dr. Hole is a professor in the UBC Okanagan School of Social Work and co-director of the UBC Canadian Institute for Inclusion and Citizenship. She is also a Tier 1 UBC Principal's Research Chair in Critical Disability Studies. Dr. Stainton is a professor at the School of Social Work and Co-Director of the Canadian Institute for Inclusion and Citizenship at UBC, and a Fellow of the International Association for the Scientific Study of Intellectual Disability.

The presentation was based on the findings of a review of international literature on individualized funding conducted by Dr. Hole and Dr. Stainton. Fifty-eight articles were included in the review from countries across the world including Australia, the UK, Europe, New Zealand, and the United States.

More than 150 people joined this session from areas across the province, representing a variety of perspectives including health care providers, families, educators and others.

Session Takeaways:

Individualized funding (IF) is defined as "funding allocated directly to an individual or, in the case of a child, their parents or legal guardian, to provide support necessary to meet disability-related needs."

The benefits of an IF model include:

- Increased self-determination and the promotion of a family-centered approach, where families decide how to use funding; and
- Increased control, choice, reliability, and flexibility in therapies and interventions for families.

The barriers that families face when accessing IF include:

- Increased administrative burden can be restrictive. Families have varying abilities to take on this burden;
- Information gaps can add complexity when navigating systems and services, such as the assessment and diagnosis processes;
- Socio-economic barriers – paying up front may cause financial hardship and compounds alienation of equity deserving groups;
- Families in rural or remote areas have fewer services available and incur higher costs for services; and
- Siloed structures between health care and social systems can frustrate families and impact their decision-making about services/supports for their child or youth.

The literature pointed to several key components that were in place when the IF model worked well:

- Clear lines of communication between families and health care/service providers, which is particularly important in early child interventions;
- Family status, social capacity, and socio-economic status – wealthier families had more positive experiences with IF;
- Access to trusted service providers and support workers directly impacts outcomes for children and youth and the quality of choice available to families; and
- Interagency collaboration is essential to minimize administrative burden and support informed decision-making when families are determining how to use funding.

Policy and Practice

Currently in British Columbia, IF is not available through a needs-based assessment. Jurisdictions vary widely and caution should be taken in adopting practices from other jurisdictions. IF in children and youth is mainly used for respite and therapies, whereas in adults it is mainly used for residential and day supports. Generally, the research suggests that when done effectively, IF does better than collective systems, but should not replace agency or collective systems. It requires a strong infrastructure, workforce, and administrative support to work well. Additionally, IF presents unique challenges in remote/rural and Indigenous communities.

Breakout Room Discussion – What Was Shared

Participants were placed in small breakout rooms (ranging from five to 15 participants per room) for a moderated discussion to discuss this question:

Given all the learnings shared today, what one or two considerations stood out for you when informing a system of services for children and youth with support needs?

The comments reflect participants' lived experiences and ideas for an effective system of services for children and youth with support needs across BC.

Participant comments have been themed into three categories:

1. Service Planning and Coordination: direct planning with families, transition planning (of any type), cross-program/ministry coordination.
2. Service Delivery: direct CYSN Services, wraparound services, workforce considerations.
3. Administration: funding, service processes and pathways (e.g., intake; prioritization), ministry roles and responsibilities (i.e., which ministry is responsible for what), and physical space.

Service Planning and Coordination

Ideas for direct planning with families centered on the availability and accessibility of information to navigate supports. Suggestions included: creating a website to map available services; supporting early identification of disabilities; and providing a finance manager to support families in managing their accounts. Overall, we heard that a new system should enable flexibility for families, recognizing the needs of children or youth may change over time. This could include regular assessments, clear decision-making processes, and easy-to-understand information to allow families to customize support plans.

The discussions revealed transition planning for youth entering adulthood is an important part of a new system, and that incorporating wraparound supports is essential for their success. Supportive housing, prioritizing additional staffing in schools, and maintaining strong relationships with service providers would ensure smoother transition periods for youth.

Further ideas for cross-program/ministry coordination included federal grants (which would enable families to be less reliant on IF), exploring adjusting the system so there are fewer opportunities for complication, and suggestions for the Ministry of Children and Family Development to work more closely with the Ministry of Education and Child Care and Ministry of Health. Strong support of the New Zealand model presented was noted, specifically integrating Indigenous participation, and the approach of providing supports across ministries and across a child of youth's lifespan to reduce gaps in services.

Service Delivery

Suggestions to improve direct CYSN services included:

- A scaffolded approach to service delivery that considers families with economic challenges (e.g., having support available to families at their entry into the system, allowing them to navigate the different components according to their circumstances and needs).
- Navigation support to assist families in accessing resources.
- Greater equity in the services provided across the province.
- A system based on a child or youth's needs, rather than diagnosis.
- Exploring a hybrid model that offers families a choice between centre-based services and IF, allowing families to move between these choices and offering the opportunity to access services independently.

Overall, participants expressed that families would benefit from greater autonomy and flexibility in making choices based on their needs.

There were recurring comments relating to wraparound services. Participants shared that it was helpful to have navigators for each service but noted that some navigator roles were more valuable than others, suggesting these roles could be revisited. Navigators/case workers should be connected to the family and must be trained to be culturally safe and able to identify appropriate resources for families. In terms of access to information, more information for families in hospital is needed; one suggestion was to have navigators at birth. Translation services are critical as this is a significant expense incurred by families; covering travel costs for families is also needed.

Regarding workforce considerations, the new system must include adequate resources, notably for administrative duties and supports. Participants expressed a desire to have staffing retention challenges addressed in residential settings and to reduce social workers' caseloads to enable them to be more involved.

Program Administration

A general need for increased funding to support families and the systems that serve them was expressed; this would enable service providers to proactively engage with families and address their specific needs. Earlier investments and additional government contributions could reduce the need for families to seek IF, recognizing this type of funding is still an important part of the system. Funds should be made accessible for a broad range of services, such as music therapy. Overall, there was a call to prioritize easing the administrative burden on families.

The discussions revealed a need for clear communication regarding prioritization procedures and reasons for service unavailability. A major obstacle identified was language barriers, as poorly transcribed resources impact service delivery; participants would like a system that empowers families, promotes cultural sensitivity, and acknowledges the ongoing efforts towards decolonization within the healthcare system. There were suggestions to incorporate stronger accountability measures, such as fee structures, into program administration.

Participant Questions and Comments Summary:

Throughout the presentation, participants shared comments and questions in the Zoom chat function related to designing a new system for children and youth with support needs:

- Hybrid models: research showed families had a more positive experience when there was a combination of collective and IF.
- Mitigating risks: with an IF model, parameters would need to be put in place to protect families, such as capping fees for services, and ensuring appropriate regulatory oversight so families are assured of the credentials and expertise of service providers.
- Timelines for reimbursement for services: in an IF model, it was noted that paying up front for services is a barrier for many families, and timely reimbursement would be important to allow families choice and flexibility, as would consideration of any Cost-of-Living increases.
- Remote and cultural communities: it is important to have experienced, local professionals to help reduce barriers for families.