

Small Group Sessions: Transitions

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Background: Literature is sparse that addresses issues related to lifespan transitions specifically for persons with autistic spectrum disorders (ASD). There is, however, a substantial literature in the more general field of developmental disability. Although much can be learned from this research (for example, in terms of predictors of independent living outcomes), there is also reason to suppose that there may be unique aspects to the experience of persons with ASD and those who support them. For instance, a distinction is made between “horizontal” transitions (i.e., relatively micro-level transitions between activities or settings) and “vertical” transitions (i.e., those macro-level transitions such as between stages of life, or with reference to major systems such as health or education). There is broad recognition that persons with ASD have particular difficulty with horizontal transitions, and it is common to consider specific supports related to these differences. This might lead to the assumption that navigating vertical transitions might also present particular challenges in ASD. However, empirical evidence on this issue is only beginning to emerge. Since transitions frequently refer to relationships between systems, it seems likely that some findings might not be readily transferable from one country to another. Thus, there is a particular need for Canadian data relevant to this topic. As an example of recent Canadian research, Levy and Perry (2008) studied professionals’ perspectives on the transition of children with ASD from Ontario’s IBI program to the public school system.

Participants in the two small group sessions were highly engaged in the topic. One powerful aspect of both sessions was hearing the language of families as they discussed their experience of lifespan transitions: “falling off a cliff”, “hitting the wall”, “dropping off the table”, entering the “void”, “starting all over at each transition”. Another overarching observation that emerged over the day was that often, transitions were defined in relation to formal systems – usually the education system – rather than individual developmental experiences or needs. That is, transitions -- such as preschool to school, junior high to high school, after high school – that are relevant only to 12 or so of the child’s/family’s first 17-18 years. Participants identified a variety of other milestones and contexts that involve important transitions for individuals and their families, such as from the stage of parental “concerns” regarding a young child to diagnosis, from pediatric to adult health care, or from living within a family context to alternative living arrangements. The following themes emerged from the two group discussions: (1) the necessity of a lifespan view of transitions; transitions are a fact of life, not an anomaly,

and (2) the importance of family systems perspectives; this might include effects on the individual, on sibling, parents, and extended family, as well as the relationships between and among these family members.

With respect to research needs, one suggestion was to build on what is known from other related research literature (e.g., re: persons with intellectual disabilities). Issues of definition and measurement were regarded as crucial: e.g., how to determine what are the most challenging transitions and how to define them; what constitutes a successful transition outcome, and how does one measure this?

One research approach that was suggested was to begin with a needs assessment, that is, to identify where gaps exist in transition services. This approach presupposes that “transition services” exist or that these are built into other services, and that the search for same will reveal gaps. One novel re-interpretation of this issue was the suggestion to look for opportunities to eliminate unnecessary transitions (that is, the idea of “seamlessness” conceived as an absence of noticeable transitions).

Another approach was to identify models of what seem to be successful programs or practices promoting transitions (that is, exemplars of ‘best practices’) and to “shine a light” on these. That is, to systematically examine the factors that might contribute to successful transitions. Once the success of small-scale programs was identified and analyzed, research efforts could shift to replication and expansion of models built on the successful template.

Recognizing the pervasiveness of transitions across contexts and over the lifespan, one participant suggested that all research projects should incorporate a component that examines transitions (where possible and appropriate). Underlying such a strategy was the idea that knowledge about transitions would accrue incrementally.

Other stakeholders and participants need to become involved in research discussions concerning transitions – funders were an important example. Employers are also important players in research surrounding the needs of adults with ASD. Perhaps issues of accountability for programs are highlighted when stakeholders such as employers are included.

In addition to funders, there is a need for input from health policy experts. What are the drivers of policy change that might influence the development of enhanced transition services? These perspectives are needed at all levels from local and provincial to national policy- and decision-makers. Contributions by health economists would be appropriate additions to research teams addressing such issues.

