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The Role of the National Longitudinal Survey of Child and Youth in the Era of the Canadian Children's Agenda

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Unlike the United Kingdom, the United States and New Zealand, until recently Canada had no population-based, nationally recognized birth cohort study or longitudinal survey of children and youth. Information on child development and its determinants, when it was considered at all, was treated the way Canada traditionally treated manufactured goods; something to be produced in other countries and simply consumed here. The weakness of this approach was not readily appreciated until child development, especially early child development, emerged as a national priority in the 1990s. Suddenly, Canada discovered that it had no information base to track the developmental trajectrories of its children and understand their life circumstances. As the political momentum that culminated in the Canadian Children's Agenda grew, so too did a movement among a broadly based research community (consisting of population health, child development, education, criminology, family and labour market studies researchers), Federal and provincial bureaucrats in key ministries, and key individuals in Statistics Canada, for a longitudinal survey that could do for life course research and policy-making in Canada what the 7-Up series of movies from the United Kingdom had done for the popular imagination. What was needed was a research platform for understanding the 'early life' factors that influence trajectories of development and health in Canada.

The emerging National Longitudinal Survey of Children and Youth (NLSCY) had four characteristics that made it especially attractive in this regard:

- it was designed as a large national random sample survey (initial sample of 22,000) with an option to over-sample in regions and/or local communities; both of which options have been exercised.
- it began with a sample aged 0-11, to be followed every other year and supplemented with newborns in succeeding waves, such that there would be 'dense' information with which to construct developmental trajectories and, at the same time, immediate data at a wide range of ages.
- since it was created as a federal-provincial-academic partnership it had a broad constituency of researchers and policy decision-makers.
- it began in 1994/95, just a few years prior to the federal-provincial agreement on the Children's Agenda, such that there was already useful information available when it came time for policy and decision making.

1. Why developmental studies like the NLSCY are important

My interests in the NLSCY were multiple. As a member of the Program in Population Health of the Canadian Institute for Advanced Research I became convinced that the origins of socioeconomic gradients in health across the life course were to be found, at least in part, in early life circumstances. This influenced my career in three ways.

First, I began to collaborate with Chris Power in her work on understanding SES gradients in health on the 1958 British Birth Cohort. It was through this work that I came to understand that physical, language/cognitive, and social-emotional development were three parallel phenomena in their role as lifelong determinants of health that, in turn, were influenced by early life circumstances. Figure 1 presents summary output from that work, focusing on the determinants of self-rated health at age 33. The figure shows an arrow, representing the life course, intersecting a bullseye, representing society at three levels of social aggregation where determinants of health are found. The figure is meant to convey the notion of an ongoing interaction between life course and society 'from cradle to grave'. As indicated by the figure, we proposed that the possible long-term exposure→expression relationships cluster into three generic models, which we labeled *latency, cumulative,* and *pathway.* By *latency* we mean relationships between an "exposure" at one point in the life course and the probability of health "expressions" years or decades later, irrespective of intervening experience. *Cumulative* refers to multiple exposures over the life course whose effects on health combine. These may be either multiple exposures to a single recurrent factor (e.g., chronic poverty or neglectful parenting) or a series of exposures to different factors. An example of the latter might be poverty, accompanied by family breakdown and dangerous neighbourhood circumstances. Finally, the term *pathways* represents dependent sequences of exposures in which exposure at one stage of the life course influences the probability of other exposures later in the life course, as well as associated expressions. For example, the divorce of someone's parents in early childhood may reduce that child's readiness to learn at school entry, which may, in turn, affect school performance, which would affect later employment opportunities and the socioeconomic trajectory throughout life.

With respect to the bullseye, at the macro level are such society-wide influences as levels and fluctuations of national income, and particularly patterns of distribution, and policies intended to affect these (e.g. income support, education, health care or employment policies). At an intermediate, or 'meso' level, are the characteristics of one's neighbourhood, community or workplace. Influences here would include how people interact with each other; levels of social trust and community participation; working conditions in the local

employment base; and the quality of local institutions such as schools, libraries, newspapers, policing and parks. At the most 'micro' level, there are the influences on health associated with private life, such as the nature and quality of personal social support: intimate relationships, friendships, and the availability of personal help when needed. From the standpoint of child development, one is most interested in whether or not the intimate environments of childhood are stimulating, supportive, and nurturing. Not all relevant influences fit neatly into one level of social aggregation. For example, 'job insecurity' and 'sense of control' are perhaps best understood as resulting from the interaction between macro, meso and micro influences on the individual at particular stages of the life course.

We examined the life course in the context of broad social influences, by incorporating the concept of macro/meso/micro-levels of social aggregation to create the parsimonious predictive model of health in early adulthood in the 1958 birth cohort presented in Figure 1. It shows the model-based odds ratios for the factors within each compartment that, together, 'best' explained self-rated health at age 33. From the standpoint of the NLSCY, and childhood longitudinal studies generally, the first important finding was the following: the effects of childhood factors, latent, pathway or cumulative, were not "explained" statistically by including society level factors, and conversely, society level effects were not "explained" by life course factors. For the purposes of this discussion the most notable odds ratio was for the latent factors (OR = 5.03). Three weakly correlated latent factors survived in the best fit model: behavioural adjustment to school at age 7, whether or not parents were reading with their children regularly by age 7, and the proportion of adult height attained by age 7. Together, poor behavioural adjustment, little exposure to reading, and slow early growth conferred a five-fold increase in the risk of fair/poor self-rated health by age 33. This pointed to the prospect that cognitive, behavioural, and physical developmental factors could each be an important life course determinant of health. As a result of this finding I approached the NLSCY from the standpoint of wanting equal quality information to be collected in each of these domains of child development.

My second career influence involved helping organize and participate in organizing the Human Development Program in the CIAR, which created an inter-disciplinary framework for understanding that the determinants language/cognitive, social/emotional, and physical development were similar to one another and that, further, the life course determinants of health were similar to the life course determinants of well-being and learning skills. From the standpoint of the development of the NLSCY these perceptions were important because it provided a strong intellectual impetus for the usually fractious coterie of diverse academics to agree on a common research platform. When the

original committees were struck to select questions for the NLSCY, five committee members from the CIAR Human Development Program took leadership in conveying this consensus to the other academic participants. Although this may seem trivial, getting a wide range of research and policy stakeholders to come to consensus on the content of a longitudinal survey of children and youth is a major achievement.

Third, I spent seven years as an academic advisor to the Federal-Provincial-Territorial Advisory Committee on Population Health, which was one of several Federal-Provincial-Territorial groups that came together to draft the Canadian Children's Agenda. In that context I served as a 'translator' of findings from the NLSCY and, as the first analyses of the NLSCY became available, I tried to ensure that they were reflected in the priorities of the Canadian Children's Agenda.

2. Initial contributions of the NLSCY

One of the principal challenges I confronted was trying to get the notion of 'gradients in child development' onto the Agenda. Until the NLSCY began, it was not widely appreciated that, by kindergarten age, significant preventable inequalities in development existed in Canadian society. To be sure, it was expected that certain groups of children would be behind the others when they reached school, but these children would be easily identified by some form of extreme deprivation – economic, cultural, or domestic. The information in Figure 2, then, came as a revelation to many observers. It illustrates the pattern of inequality in receptive language development by kindergarten age in Canadian society (from the NLSCY). It shows a steep gradient in the risk of receptive language delay, increasing *gradually* from the children of the highest income Canadian families to the poorest, such that the poorest 10% of children are at approximately 5-fold greater risk of language delay than the richest 10%.

The pattern of gradually rising vulnerability with declining family income could well have been predicted based upon studies from other countries, but it was not anticipated by Canadian policy makers, nor were its implications understood. Inspection of Figure 2 shows that, although those at the bottom of the family income spectrum are 'most at risk,' nevertheless 'most of the children at risk' are spread more thinly across the more numerous middle-income groups. Gradients were also seen for many other pre-school developmental outcomes assessed in the NLSCY. Dafna Kohen and I showed a family income gradient for behavioural development and Figure 3 shows a similar gradient for recreational activity.

The basic quantitative interpretation of the gradient proved to be surprisingly difficult to convey to policy-makers. Moreover, understanding and accepting it was made more difficult still by the fact that its implications for a public commitment to child development were profound. The prior expectation, of narrowly circumscribed 'at risk' subgroups in the population, had the broad policy implication that a children's agenda should be composed of a series of targeted problem-oriented strategies. In contrast, the implication of the gradient is that, if we want to make a meaningful improvement in the state of early child development, we must find ways to create 'universal access to the conditions for healthy child development'. Although the level of challenge may be different in different walks of life, nonetheless challenges needed to be addressed all across Canadian society. *Although this point was a 'tough sell' it is important to understand that the principles of 'gradient flattening' were, in the end, incorporated into the Canadian Children's Agenda.* Moreover, as of this writing (prior to the Federal election) gradient flattening continues to be reflected in the programs that are emerging from the Agenda; for instance the QUAD (quality; universally inclusive; accessible; developmentally oriented) principles underlying the federal-provincial transfers for childcare. This approach would not have been adopted without timely evidence from the NLSCY. Evidence of gradients from studies in other countries would not have been sufficiently convincing for Canadian policy makers to face up to the far-reaching policy and program decisions that must be taken in order to address challenges to child development that are spread broadly across society.

3. Creating and Evaluating an 'Outcome-oriented Social Program'

Although it has never been officially articulated this way, the Canadian Children's Agenda has the potential to become Canada's first 'outcome-oriented social program'. That is, there currently exists an implicit commitment, among the responsible jurisdictions, to measure whether or not child developmental outcomes improve concurrently in time with the roll-out of the Agenda and, it would follow, to continuously modify the program components until substantial and sustainable improvements in child development occur. It is not the role of the NLSCY, or longitudinal studies in general, to be the primary child developmental outcome indicator for such a new social program. To fulfill this role we need a serial cross-sectional indicator that can be feasibly implemented at the population level; that will allow us to track trends over time in child developmental outcomes in a manner analogous to infant mortality or low birth weight.

In this section I argue that the role of the NLSCY and other child longitudinal studies is to provide an ongoing supply of information on developmental trajectories, and, in particular, on the determinants of 'successful' and 'unsuccessful' developmental trajectories. This information, then, should become a key source of insight for continuous improvement of the mix of programs under the Canadian Children's Agenda. I believe that the NLSCY has already contributed in that way, as I shall describe later. Next, however, I would like to discuss the Early Development Indicator (EDI) as a candidate for the serial cross-sectional indicator.

The Early Development Indicator was developed in the 1990s by a team of Canadian researchers led by Magdalena Janus and (the late) Dan Offord at McMaster University. It was designed to be a population-based tool for assessing the state of child development at kindergarten age, useful for both communities and government in understanding ECD within their jurisdictions. It comes in the form of a checklist that can be filled out by kindergarten teachers after they know a child for several months. The EDI takes approximately 20 minutes per child to fill out, such that an entire class can be assessed for the cost of a one-day kindergarten teacher buy-out.

A five-year validation process took place during the late 1990s before the EDI was proposed for use in local communities. It was pilot tested on approximately 16,500 children in Toronto, North Bay, Baffin Island, Ottawa, and New Brunswick. In this way unreliable items and items that violated the UN Charter on the Rights of the Child were removed; scales were defined; and the range of utility of the tool was determined. The EDI is valid for interpretation at the level of the group, and can be analyzed at the level of the individual, but it is not an individual *diagnostic* instrument. It is valid in the age range of kindergarten, plus or minus one year; and gives unbiased results for aboriginal and English as a Second Language children. Since implementation, further validation exercises have been undertaken in Australia and BC. These exercises have been broadly consistent with the original validation. Most important, the EDI has been demonstrated to be predictive of individual student achievement on standardized tests of reading and arithmetic at Grade 4.

The EDI has five major scales: physical, social, emotional, language and cognitive, and communication skills and general knowledge. The five scales map directly onto the three broad domains of early child development: physical, social-emotional, and language/cognitive that have lifelong influence on health, well-being, behaviour and learning skills. Thus, the EDI provides information that can be interpreted both backwards and forwards in time. The primary 'direction of interpretation' for the purposes of early child development is backwards in time. That is, the results of the EDI, at the level of the group, can

be construed to reflect the qualities of early experience that a particular group of young children have had up to that point in their lives. However, the EDI can also be interpreted prospectively, in that the results frame the challenge that families, schools, and communities will have in supporting their children's development from kindergarten onward.

The principal parameter generated from each scale of the EDI is 'vulnerability' and for each scale there is a score that serves as a 'vulnerability threshold'. Children who fall below that score are said to be 'vulnerable' in that area of their development, The interpretation of 'vulnerability' is that the child is, on average, more likely to be limited in their development in that area than children who fall above the cutoff. Because of the nature of the EDI, this is meant to be an interpretation at the level of the group. In other words, it is a meaningful use of the EDI to say something like *"20% of children in neighbourhood A are vulnerable in their physical development, whereas in neighbourhood B only 5% are vulnerable"* rather than comparing two individual children.

In British Columbia, we have mapped the 'proportion vulnerable' by geographic area for each scale of the EDI, and for one or more scales, for the whole province. Figure 4 shows the proportion of children who were vulnerable on one or more scale of the EDI according to the 59 school district areas of BC and Figure 5 shows an individual school district broken down according to neighbourhood[1]. This is the 'holistic' measure of ECD, covering all domains of development; in other words they represent the 'differences that make a difference' for child development. It should be noted that the range of vulnerability by nieghbourhood within the one small school district shown here is as large as across all 59 school districts in BC. I propose that, for an outcome oriented social program, it is serial cross-sectional information like this that will allow us to determine how much progress has been be made in child development during the era of the Canadian Children's Agenda.

4. The Role of the NLSCY in Supporting an Outcome-oriented

[1] The approach to neighbourhood mapping that we developed quickly became the popular standard for the province. This approach, which we have refined over the past several years, involves mapping child development according to the neighbourhood of residence of the child, rather than the census unit, school catchment area, or the school attended. By creating neighbourhoods of 40 children or more, we ensure statistical stability and anonymity in the results. Yet, thanks to the co-operation of Statistics Canada, we have been able to display socioeconomic information according to our neighbourhood boundaries. Thus, the basic output of our EDI work is a package of neighbourhood maps, presented scale by scale and accompanied by a series of socioeconomic maps, that are made available to the local inter-sectoral coalitions for ECD and, also, to the MCFD for strategic planning in policy, programs, and community development for children.

Social Program

The type of information that is generated through the use of the EDI shows how early development is distributed by neighbourhood and school but does not directly provide strategic insight into the determinants of the differences we see. This latter is an important role for the NLSCY that, to date, it has fulfilled rather well.

Figure 6 lists some of the 'determinants' of early child development in Canada according to a rough scan of the results of various analyses of the NLSCY where cognitive and/or behavioural outcomes have been used. By kindergarten age in Canada, development seems to have been influenced by factors at three levels of social life: the family; the neighbourhood or local community; and the broader society. At the level of the family, income, maternal education, and parenting style (authoritative versus authoritarian, disengaged, or inconsistent) each make a difference. This is consistent with a broader literature suggesting that the qualities of stimulation, support and nurturance in intimate circumstances matter and that these qualities, in turn, are influenced by the resources that families have to devote to child raising (represented by income); to their style of parenting; and to their tendency to provide a rich and responsive language environment (often, but not always, associated with maternal levels of formal education).

At the level of the neighbourhood, children growing up in areas that are perceived to be safe, and that are perceived to be 'cohesive' in relation to children – (*i.e.* where children are treated like they belong there) – are less likely to be vulnerable in their development than children from similar family backgrounds living in 'unsafe' and 'non-cohesive' neighbourhoods. Children who have stable neighbourhood environments during their early years tend, also, to have more successful developmental trajectories than those children who are constantly changing their place of residence. Similarly, children from family backgrounds with multiple developmental risk factors do better in mixed socioeconomic neighbourhoods in their very early years than they do in ghettoized areas.

Finally, at the level of society, our analyses of the NLSCY have shown a broad pattern that, as one goes down the socioeconomic spectrum, child development becomes increasingly sensitive to the nature of childcare arrangements. At the top end of the socioeconomic spectrum we were not able to find any differences in receptive language development among children staying home, subject of informal care, or in licensed/regulated care environments. However, at the lower end of the spectrum there was a demonstrable advantage associated with licensed/regulated care compared to the alternatives, and this advantage persisted into the primary school grades.

The factors listed in Figure 6 and the interpretations I have placed upon them are radically incomplete, vaguely specified, and are not subject of a broad consensus of Canadian researchers and policy-makers. Nevertheless, Figure 6 demonstrates the potential value of the NLSCY in providing useful insights into the determinants of child development.

- It demonstrates how the state of child development in a society can come to be an 'emergent property' of a complex of factors, many of them modifiable, at the intimate, civic, and societal level.
- It provides insights into the factors that underlie the gradients shown in Figures 2 and 3 and helps to explain why, at the ecological level, 43% of the neighbourhood variation in vulnerability on the EDI in BC can be 'explained' by socioeconomic factors.
- It helps explain why the level of variation in 'vulnerability' in BC (and elsewhere) is greater at the neighbourhood level than at the school district level.
- It provides insights into where to look and how to look for strategies that might improve child development.

This latter point is very important and worth further consideration. In British Columbia I have been traveling from community to community for the past 4 years showing local neighbourhood EDI maps to the regional coalitions that are trying to roll out the children's agenda, and discussing strategy with them. In that context I have shown Figure 6, or variations on it, several hundred times and I have become acutely aware of how this form of 'research transfer' plays out at the local level. What I have discovered is that the neighbourhood variations in EDI scales create a large appetite for understanding the factors that underlie the variations; which ones are modifiable; and which modifiable factors are under local, provincial, and/or national influence. Thus, although it has many methodological weaknesses, the information from the NLSCY found in Figure 6 has proved itself very useful in the practise of the Canadian Children's Agenda.

5. The NLSCY as a Tool for Research and Policy

At present, many of the features that should allow us to use the NLSCY as a tool for research and policy-making are in place. Much of the data is available through the Statistics Canada Research Data Centres and NLSCY users are among the most common users of those Centres. Syntax files have been developed and put into the public domain to assist researchers. There is a SSHRC funded network of young scholars who work on the data and, to date, several hundred papers have come out in the peer reviewed and grey literature, as well as one peer-reviewed book. Various provinces have strategically over-sampled using the NLSCY and are turning to it as a source of information for accountability purposes under the terms of federal-provincial transfer payment

agreements. Through the Understanding the Early Years (UEY) program community cluster data has been collected in several dozen Canadian communities. Yet, the NLSCY is not currently seen as a success and its future is uncertain. Why has this happened?

In part, the answer lies in the inevitable trade-offs that come about in a complex, multi-stakeholder longitudinal study, compounded by the problems of maintaining an endeavour with many stewards but no single long-term principal investigator. Although the NLSCY covers a wide range of topics, it does so superficially, such that no individual content discipline is satisfied with the data. Over time specific questions and response categories have changed, making longitudinal analyses difficult or invalid. Response rates, especially to the school-based aspects of the survey, have not been high. Technical problems, barriers, and delays of various sorts still make using the data cumbersome for hard-pressed graduate students. The community cluster data was never returned to the communities that collected it and, unlike the National Population Health Study and the Canadian Community Health Study, no efforts have been made to date to make the data 'linkable' to provincial health services and education records.

Does all this mean that it is time to abandon the NLSCY? The answer to this is 'no'. Because of the investment that was made in the first decade of the survey it is, by far, our richest source of information on the development of Canadian children. Unlike many of the earlier birth cohort studies, it has explicitly focused on development, not just on health and well-being, and has sampled every other year rather than once every half decade or so. These decisions mean that we have an astonishingly 'thick' core of developmental data that will only become more valuable as the years go by, when it becomes possible to study which early childhood factors have an impact on health, employment, family formation, well-being, etc later in the life course. Given what I have said so far, I think that the future of the NLSCY should be based upon addressing three issues.

1. How can we most effectively use current NLSCY data to inform the roll out of the Canadian Children's Agenda? I have outlined above what I think the role of the NLSCY should be, but we need a broader consensus among policy-makers and researchers regarding this role. The discussions here should include a sampling of those individuals across Canada who have emerged as successful early child development community coordinators.
2. How do we go about following the NLSCY sample over time? Beyond age 25 there is really no need for biennial follow-up. Based upon the experiences of other studies, a five-yearly follow-up would probably do. On the other hand, the priority of re-involving non-responders needs to be

intensively resourced and opportunities for follow-up and efficient supplementary data collection through record linkage need to be facilitated.

3. How does the NLSCY fit with all the other population studies emerging in the public domain in Canada? This basic question gives rise to a series of particular questions. For example: should the NLSCY sample be 'picked up' by other studies as the children age? Should their parents and grandparents be sampled for the proposed CIHR multi-generation study? Should the NLSCY be seen as a hypothesis base for other studies? Should biological measures be taken on the NLSCY sample, such that it works in conjunction with the Physical Measures Study?

None of these questions will receive an adequate answer unless there is an ongoing commitment to build an organized system of human development statistics for Canada. At present, all the necessary institutional pieces are in place to achieve this goal: Statistics Canada, the Canadian Institute for Health Information, the Canadian Council on Learning, the statutory research councils (especially CIHR and SSHRC) and Centres of Excellence in relevant fields, and the key federal and provincial ministries and federal-provincial advisory committees. All that is lacking is good will and a common understanding among the key players that improving human development should be the paramount goal of a successful society. But that is a lot to ask.