

Olly Olly Oxen Free (or Ally Ally in Free): Playing Hide and Seek in Allocating Resources for Child and Youth Health

Mary-Ann Hiltz, Craig Mitton, Neale Smith, Laura Dowling, Matthew Campbell, J. Fergall Magee, Jennifer L. Gibson, Shashi Ashok Gujar and Adrian Levy

TABLE 1.
Characteristics of residents in accredited and non-accredited LTC homes in Ontario, 2010^{††}

Theme	Subthemes	Description
Diversity	Economies of scale	- Pediatrics is less able to capitalize on economies of scale. - Small populations require developmentally-appropriate resources (e.g., multiple sizes of hospital gowns). - Small runs mean fewer vendors and a lack of substitutable products. - Variability in individual levels of development makes it difficult to standardize processes of care through clinical practice guidelines or measures of effectiveness. - Delivery of healthcare to children is often more service-intensive, such as requiring overnight stays that may not be necessary when the same procedure is performed in the adult population. - This has implications for staffing and remuneration of pediatric healthcare providers. - Some procedures may be rare but qualified personnel must stand ready to do them. Small populations require developmentally-appropriate resources (e.g., multiple sizes of hospital gowns).
	Timeliness	- Many pediatric services require timely delivery; these health problems have to be addressed and managed within a certain critical window. Waiting can lead to chronic effects and child patients may be forever profoundly impacted. - Celiac disease is an example of this trajectory. If untreated in childhood, patients develop osteopenia – thinning of the bones – which cannot be reversed even by subsequently improved diet and nutrition. - Another example is PKU (phenylketonuria), which has now long been known to lead to irreversible impairment if not treated in timely manner. Thus, traditional wait-time management strategies may not always be appropriate in the pediatric context.
Outcome measures	Long time horizons	- Measurement in the pediatric healthcare context is challenging. Long time horizons for assessing the outcomes of services are typical: costs accrue early but gains are realized often years or decades in the future, well beyond the term of one political cycle. - Obesity and mental health are examples. In both of these instances, the experience in the developmental years manifests during adulthood. - In other cases, interventions in child health come with long-term and unexpected health effects. We saw the emergence of post-polio syndrome in the past; more recently, the after-effects of childhood cancer treatments have been recognized as a concern for patients and families (Bellett, 2015).

Theme	Subthemes	Description
	Co-production of key outcomes	- A large amount of money is spent in every province on child health overall through initiatives such as housing, recreation and education in addition to healthcare; however, there are few effective mechanisms for coordination between these sectors. Programs operate within ministerial silos. - Healthy Child Manitoba is one model for an alternative approach that is governmental, but more importantly inter-ministerial (Jenkins et al, 2008). - Child health outcomes may be difficult to attribute to any single intervention. Many outside influences contribute to the co-production of outcomes. More narrowly defined programs may end up being prioritized over more complex, multi-factorial issues, such as mental health, due to these challenges.
	Barriers to data collection	- There are ethical obstacles to obtaining data about the outcomes of child and youth health services. - Evidence collection mechanisms are weak, e.g., “adoption and implementation of EHRs in pediatrics lags behind other medical fields” (Starmer et al, 2010). - Children depend on adults to obtain healthcare and to report on health outcomes of that care. Younger children may be less able to self-report their experiences with illness and care. “Parents and their children may have different perceptions of what defines health or have different levels of satisfaction with the care they receive” (Mangione-Smith and McGlynn, 1998). - The difficulty of capturing the pediatric patient’s preference and perception as well as that of the family adds to the complexity of implementing PSRA processes in this setting. - Efforts to improve pediatric patient-reported outcome and experience measures may contribute to improved evidence-informed decision-making (Tadic et al, 2013).
Engagement	Large geographic catchments	- Pediatric patients receive some services (like tertiary care) only episodically, but frequently encounter the wider healthcare system and may interact with many healthcare providers over a wide geographic area. As a result, there is a need to coordinate with many healthcare agencies and providers. - Typically a children’s hospital serves a large catchment area and must accommodate the needs and preferences of diverse urban, rural and remote communities.
	Mandates and transitions	- The age of majority arbitrarily shifts youth to the adult system even when no change in care needs occurs simultaneously; this transition affects care delivery, patient–provider relationships and health data collection. - One example is cystic fibrosis, which used to be primarily a pediatric disease but has evolved into a lifelong chronic condition as treatments and prognoses have improved. - Pediatric institutions may push the edge of their responsibilities in order to provide continuity and fill gaps during transitional periods.
	Patient, family and public engagement	- Though children and youth lack direct political voice, they often have strong advocates. Providers and the public usually see children as a sympathetic and deserving group and can be very passionate about their care. - When organized, the voice of parents, caregivers and support groups is highly effective and can generate results in terms of access to services. However, strong family and patient group advocacy does not always occur with consideration to trade-offs within the health system as a whole. - Further, the health needs of young people generates passion and compassion, which can be accompanied by philanthropic contributions to hospital foundations. However, these dollars often go towards discovery research, specialized medical equipment and the development of new space, rather than service delivery. - Similarly, healthcare providers in the pediatric context are a source of strength for advocacy efforts. Providers often bring a deep emotional commitment to their patients and caring relationships are developed over long periods of time. However, their passionate connection with patients they have seen grow up under their watch may make it harder for them to be objective about the “value” of a young life when compared with other resource allocation options (which works against the principles of rational PSRA).