

Family Advisory Committee Minutes
 February 25, 2016, from 7pm-9pm, Conference Centre

Item No.	Item	Person	Discussion/Action/Timeline
1.0	Introduction & Approval of Minutes	All	Anyone interested in joining FAC executive is encouraged to let Amir know.
2.0	Subcommittee Work	All	
3.0	BRI Scientist Presentation	Marilyn Ballantyne	<ul style="list-style-type: none"> • Major Healthcare Transition Milestone – preterm infants transitioning from neonatal to developmental/rehab services • How are life’s typical milestones different for kids with special needs? • Parental Health linked to child’s health & wellbeing • 25% of families disengage with Health Services as a result of their experience in NICU • Stressors include: Fear of the unknown, Low degree of info. Exchange, Not included as part of healthcare team <p>Areas of Support: Being a valued/engaged member of team, Regular info sharing</p> <p>14 Parents interviewed on their lived experience Many were hopeful & felt embraced once they came <u>Holistic Care</u>, Guidance/Information (a navigator from time of diagnosis all the way through the journey), Human connection with peers and professionals all important What can we do while we’re waiting for services? When families miss many appointments – why is it? Overwhelmed, scheduling challenges. Feel judged coming the next time for having missed. Warm Welcome to HB is so important. FAC’s goal to develop Welcome Orientation will go a long way toward achieving this.</p>
4.0	Quality Improvement Plan	Sonia Pagura	<ul style="list-style-type: none"> • Circling back from initial engagement of FAC in December, 2015. • After meeting with us, Youth and Children were engaged through surveys, meetings and focus groups. • Feedback from all 3 groups has been incorporated into the

			<p>current QIP draft</p> <ul style="list-style-type: none"> • FAC was asked if they felt that all feedback was adequately represented • Summary of Measures removed from the QIP was reviewed and assurances given that while not on the QIP, they are still being monitored (e.g. Authentic Partnership)
5.0	Family Leader Accreditation Group	Sonia Pagura	<ul style="list-style-type: none"> • Client engagement embedded in each standard now. • Ambulatory Care is new standard • Rethink how we engage families in Accreditation. 2 FL's on every team • Quarterly updates from FLAG (Family Leader Accreditation Group) • 11/14 spots have been filled to date. If anyone has any interest in joining Ambulatory Care & Infection Prevention have openings. • Time commitments are 45 hrs. over 18 months • April 19 7 – 10am Launch – All are welcome.
6.0	Youth Advisory Council Update	Cristina	<ul style="list-style-type: none"> • Assisted Feb. Youth Drop-in, a social event for current & former clients aged 16 – 29. Next one is May 14 6 – 9pm. • Participated in a focus group on Learn the Lingo providing feedback on definitions of words such as Discrimination, Confidentiality & Autonomy • Currently planning for their role in Accreditation 2017 – requests already received for YAC support
7.0	Sr. Management Team Update	Julia Hanigsberg	<ul style="list-style-type: none"> • Julia reviewed impact of today's Provincial Budget • 1% increase in Hospital Budget • Special Needs Strategy: \$250 million per year for two years into home care & \$333 million over five years to redesign and consolidate autism services in Ontario • Employment strategy for people with Disabilities <p>Patients First proposal Goals – improved co-ordination of services, enhanced access Paper does not contain many details. Government is looking for feedback. Observations: Pediatric is not mentioned in the paper. Our needs are different. Caregivers' needs are interconnected with child's needs. Transitions to adulthood. We want the Ministry to recognize the need to separate out Kids' needs. Legislation will start to move ahead in the Spring based on this paper.</p>

			<p>FAC members raised the importance of the 3 Ministries (Health, Child & Youth & Education) to work together</p> <p>This is just the beginning of the process. HB's response, in conjunction with Sick Kids, is to ask the Ministry to take a pause and let us help you ensure kids are being treated separately and Families need to be involved throughout the rest of the process.</p>
8.0	Board of Trustees Update	William Onuwa	<ul style="list-style-type: none"> • Board member for 4 years. • Information is important to families. How can Board help support Families with gaining information? • FAC members suggested a package of information be developed by HB for parents to help them through their journey • Immigrants face extra challenges such as Language barriers, family dysfunction, etc. • Board should look to see where families can be further engaged? • Are there any family leaders on the Board? No, but there are families. Maybe there should be? • Is there an opportunity for Board members to come and see first-hand what it's like to be a client here (waiting rooms, visit clinics)? • Board members could visit families in their homes like current U of T Med students program.
9.0	Meeting Adjourned	All	<ul style="list-style-type: none"> •