

**Lindsay, S., Cagliostro, E., and McAdam, L. (2019). Meaningful occupations of young adults with muscular dystrophy and other neuromuscular disorders. *Canadian Journal of Occupational Therapy*, 86.**

### **Appendix A: Interview Guides**

These interview guides were developed based on a comprehensive review of the literature on transitions to adulthood among youth with disabilities (Coleman 2003; Field et al., 2012; Kennedy et al., 2005; Kingsnorth et al., 2011; Muchenberger et al., 2012; Tsybina et al., 2012). They have been piloted and used in previous studies on transitions for youth with spina bifida and youth with complex care needs (Lindsay & Hoffman, 2015).

1. Can you tell me a bit about the DMD clinic at [pediatric hospital] and your experiences there? Which healthcare professionals did you see there?
2. Can you tell me about your last couple of visits to the DMD clinic at [pediatric hospital] what did you do? Who did you see/meet? Do you remember anything they told you?
3. Where do you go now when you need to see a doctor or nurse?
4. Since being transferred to [adult health care facility] and having your last visit with these professionals at [pediatric hospital], how has your health been? What would you say has gone well/the way you expected with your health care/transfer to adult care?  
  
[Probe for community/health care linkages, readiness, transition process, appropriateness of roles/team members, parent involvement]
5. Thinking back to when you were attending the DMD clinic at [pediatric hospital], what stood out from your visits with these professionals as being the most helpful/valuable in preparing you to leave [pediatric hospital] some day?  
  
[Probe for community/health care linkages/communication, opportunities for social

participation, readiness, identification of specific roles, planned visits]

6. If you could go back in time to when you were still at [pediatric hospital], what advice would you give yourself to help prepare you to transfer to adult care? What advice would you give your care providers?
7. What services are you currently receiving at [adult health care facility] that have helped you to transition? (i.e., adult health care services, independent living, work, housing etc.)? In your day to day life, what do you find most easy/difficult?
  - a. Do you encounter any challenges in accessing health / social services (housing, employment etc.)
8. Is there anything else you would like to tell me about your experience transferring to adult care that we didn't get a chance to talk about?

## **Parent / caregiver interview guide**

9. Can you tell me a bit about the DMD clinic at [pediatric hospital] and your and your [son's] experiences there? Which healthcare professionals did you see there?
10. Can you tell me about your [son's] last couple of visits to the DMD clinic at [pediatric hospital] what did you do? Who did you see/meet? Do you remember anything they told you?
11. Where does your [son] go now when you need to see a doctor or nurse?
12. Since being transferred to [adult health care facility] and having your last visit with these professionals at [pediatric hospital], how has your [son's] health been? What would you say has gone well/the way you expected with your [son's] health care/transfer to adult care?

[Probe for community/health care linkages, readiness, transition process, differences between pediatric and adult services, appropriateness of roles/team members, parent involvement, client/professionals' competency in managing their transition]

13. Thinking back to when your [son] was attending the DMD clinic at [pediatric hospital], what stood out from your visits with these professionals as being the most helpful/valuable in preparing you to leave [pediatric hospital] some day?
  - a. Was there anything missing/what was least helpful/valuable?
  - b. How did these visits affect other areas of your [son's] life? (Beyond your physical and psychological health?)

[Probe for community/health care linkages/communication, opportunities for social participation, client feelings of readiness, identification of specific roles, planned visits]

14. If you could go back in time to when your [son] was still at [pediatric hospital], what advice would you give yourself to help prepare you to transfer to adult care? What advice would you give your care providers?
15. What services are you currently receiving at [adult health care facility / elsewhere] that have helped your [son] to transition? (i.e., adult health care services, independent living, work, housing etc.)? In your day-to-day life, what do you and your [son] find most easy/difficult?
- a. Do you encounter any challenges in accessing health / social services (housing, employment etc.)

## **Practitioners Interview Guide**

1. Can you please describe the DMD clinic to me?
2. Did you use the any transition tools (timeline, readiness checklist etc.)?
3. Has the preparation of DMD clients been useful for facilitating their understanding of their condition and the transition process?
4. How has this transition of DMD clients benefited pediatric hospital/ [adult health care facility], its service providers, and its clients/families? (or, how do you think it will benefit them in the future?)
5. What have been the challenges with the transition of DMD clients and what have been its successes?
6. Are there any gaps or barriers in the transition services?
7. If money were no object, would you change the transition of DMD clients in any way?