Integrating Ethics in Paediatric to Adult Transitional Care

**Do we need a clinical guidance tool?**

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**BACKGROUND**

Why ethics in transition in neurodisability (ND)?

In the context of ND, the goal of autonomy is valuable, however, needs to be approached with caution (Racine et al, 2014)

Care for young people with ND needs to be responsive to emerging autonomy and interdependence (Gorter & Gibson, 2016)

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**INTEGRATIVE FRAMEWORK ON ETHICS IN TRANSITIONAL CARE**

1. Autonomy
   - Respect youth capacity for participation in decision-making
   - Recognize transition as a staged process
   - Examine youth right to self-determination vs. best interest
   - Facilitate gradual uptake of responsibility

2. Trust & relationships
   - Recognize interdependence
   - Paternalistic models may create dependency
   - Recognize differences in communication styles
   - Considerations re: truth telling about availability of resources

3. Equality & justice
   - Parents’ right to self-determination
   - Youth decisions to opt in/out
   - Parents desire to be informed

4. Confidentiality
   - Citizenship rights/right to participate
   - Hidden issues re: dominant culture, values, institutional practices, standards
   - Mismatch between capacity of young persons and available resources to support autonomy

5. Ethical in transitional care
   - Expand transitional care beyond health care (education, leisure, sexuality, housing etc.)
   - Incorporate life and existential issues and questions

Sources: Racine et al, 2014

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**SCOPING REVIEW PROTOCOL** Five-step scoping review process 1, 2

1. **Step 1** Identify key research questions
   - What ethical principles are explicitly/implicitly embedded in the vision of transitional care programs?
   - What ethical principles are embedded in service delivery guideline(s) of transitional care programs?
   - Which ethical issues/situations have been encountered in transitional care?  
   - What strategies have been employed to recognize and address these ethical issues?
   - What key policy/practice recommendations can be developed from this knowledge synthesis?

2. **Step 2** Identify relevant studies (n=1161)

3. **Step 3** Study selection (n=23)

4. **Step 4** Chart the data

5. **Step 5** Consultation

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**WE WELCOME YOUR INPUT!**

Researchers, clinicians, young adults and caregivers will be invited to review results and offer opinions

In your experience, what transition practices produce positive outcomes for young people with ND?

What practices can promote autonomy, respect needs & capacities and trusting relationships?

How should patient values & preferences integrated into transitional care programs?

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