SHARE Transition Plan

Talking about transition with young people with developmental disabilities and their families

Introduction

SHARE Transition Plan is a guide for healthcare providers to discuss transition to adulthood with young people with intellectual and developmental disabilities and their families. It covers five key areas important for planning a transition from child to adult services: Supports for communication and capability; Healthcare transition and transfer; Activities and engagement; Relationships and wellbeing; Exploring services and supports (SHARE).

Transition planning involves setting goals in these areas over time. Identifying transition goals helps a young person to develop skills and obtain supports that help achieve better health and quality of life in adulthood.

How to use this tool

Transition planning can span from 12 to 21 years old, and beyond in some cases. It is recommended to start a conversation about transitions early. This tool can be used as often as resources allow and whenever patients and families are interested in discussing transition topics. Regularly get back to this discussion and review the goals. Practice steps:

A. OPEN CONVERSATION: Ask the young person and their family what they feel are important topics to talk about in planning for adulthood (5 minutes). If they completed the SHARE Checklist[1], review answers and highlight priorities.

B. GUIDED CONVERSATION: A minimum of 10-15 minutes conversation time is recommended. This is a guide, not a checklist. You do not have to cover each item in the list. Focus on patient and family priorities.

C. SET GOALS: Write three specific goals for the patient, family and provider based on your discussion in part A and B. Make at least one goal "fun" and completely focused on the wishes and interests of the young person. Family goals and system goals are practical and necessary but should not overshadow the young person exploring their own interests, values, and relationships.

Identify next steps and consider referrals to a social worker, children's treatment centers, counselling, employment programs and/or those helping the young person with transition planning in the school for follow up. Book follow up appointments as needed.

Discuss the five SHARE categories:

- **SUPPORTS FOR COMMUNICATION AND CAPABILITY:** Discuss self advocacy, informed consent and rights around decision making in healthcare and any needed supports.
- **HEALTHCARE TRANSITION AND TRANSFER:** Healthcare transition is the process of acquiring skills and supports needed for managing health as an adult. Healthcare transfer is when pediatric service ends and transfers to adult providers.
- **ACTIVITIES AND ENGAGEMENT:** Discuss planning for life after high school by exploring interests, skills and opportunities early and often. For example, further education, employment, volunteering, recreation, day programming, respite.
- **RELATIONSHIPS AND WELLBEING:** Promote resilience by encouraging important social connections (family, friends, partners, community), considering evolving identity, the young person's support needs, and emotional health.
- **EXPLORING SERVICES AND SUPPORTS:** Explore services, programs and funding for the young person and caregivers to research and apply for.

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Surrey Place Developmental Disabilities Primary Care Program

Patient Name		DOB:
First	Last	

Caregiver Name	
First	Last

Transition visit		
Visit 1:	Visit 2:	Visit 3:

A Open conversation: *Ask the young person and their family what they feel are important topics to talk about in planning for adulthood (5 minutes). If they completed the SHARE Checklist[i], review answers and highlight priorities.*

Notes

B Guided conversation: *Review the SHARE areas for planning the transition to adulthood. Explore SHARE items based on priorities and time available. You can come back to this list at any time. Use the check boxes to keep track of which items you discussed and which actions were taken.*

SUPPORTS FOR COMMUNICATION AND CAPABILITY

Ages 12-21 Relevant for all ages

Discuss:

Discuss the patient's skill level for:

- ☐ Reporting symptoms by expressing pain and illness verbally or non-verbally.
- ☐ Knowing when and how to get help if sick.
- ☐ Carrying emergency alert/information.
- ☐ Participating in healthcare discussions.
- ☐ Expressing needs and fears in healthcare (eg, list of questions, slower explanations, pain management, previous bad experiences).
- ☐ Communicating about their condition, treatment options and management.
- ☐ Discussing pros and cons of a healthcare decision.
- ☐ Making the decision.

Actions:

- ☐ Record who trusted supporters are for managing health day-to-day, arranging healthcare, going to appointments.
- ☐ Clarify and record who the legal decision maker would be if person is incapable for a decision.
- ☐ Provide information (handouts, links) explaining legal rights around decision making in healthcare.
- ☐ Refer for legal aid if needed to clarify.
- ☐ Recommend keeping a written summary of medical information, care needs, emergency contacts to help communicate information quickly to new people. Example: About My Health[ii]
- ☐ Offer time to meet individually (without caregivers). Review confidentiality and limits of confidentiality.

Notes

HEALTHCARE TRANSITION AND TRANSFER

Ages 12-16

Discuss:	Actions:
TRANSFER ☐ Importance of finding a family doctor and how to do this. ☐ Timing of transfer to adult providers and any important patient/family preferences. ☐ How to get copies of medical reports and encouraged family to keep copies of key reports.	**TRANSITION** ☐ Provide the SHARE Checklist[ii] to patient and caregivers. ☐ Set a specific health related goal with patient.

Ages 16-21

Discuss:	Actions:
TRANSFER ☐ Importance of finding a family doctor. ☐ How to obtain pediatric health records.	**TRANSFER** ☐ Complete the Healthcare Transfer Tool[iii] to identify gaps and problem solve gaps with patient and family. **TRANSITION** ☐ Provide the SHARE Checklist[ii] to patient and caregivers. ☐ Set a specific health related goal with the patient.

Notes

ACTIVITIES AND ENGAGEMENT

Ages 12-16

Actions:

Encourage patient and family to
- ☐ Join at least one after school activity to explore an interest/hobby/activity.
- ☐ Make 1-2 life skills goals as appropriate to ability.
- ☐ Review school's Individualized Education Plan (IEP) and suggest a 'transition plan' section.

Ages 16-21

Actions:

Encourage patient and family to
- ☐ Plan for daily activities after high school ends.
- ☐ Joining at least one after school activity: employment, volunteer, recreation.
- ☐ Make 1-2 'life skills' goals as appropriate to abilities.
- ☐ Review transition plans from school (IEP) and specific opportunities for community inclusion.

Notes

RELATIONSHIPS AND WELLBEING

Ages 12-16

Discuss:

- ☐ Social supports and flag any concerns (eg, friendships, school, bullying, internet).
- ☐ Mental health for youth - referrals for specialists, skills groups, counseling.
- ☐ Puberty and sexuality.

Actions:

- ☐ Offer the young person and primary caregiver an opportunity to discuss their own concerns privately.
- ☐ Encourage family to connect with informal social support (family, friends, community).
- ☐ Assist in connecting to mental health supports.
- ☐ Discuss privately with caregiver their stress levels. Encourage caregiver to seek supports for own health.

Ages 16-21

Discuss:

- ☐ Social supports and flag concerns (eg, transition out of school, social isolation, internet).
- ☐ Mental health for youth and caregiver - referrals for specialists, skills groups, counselling.
- ☐ Puberty, sexuality and dating.

Actions:

- ☐ Ask youth and primary caregiver (if relevant) if they would like to discuss their own concerns privately.
- ☐ Encourage patient and family to connect with informal social supports (eg, family, friends, community).
- ☐ Assist in connecting to mental health supports.

Notes

EXPLORING SERVICES AND SUPPORTS

Ages 12-16

Actions:

Encourage family to

- ☐ Review the end dates for current services and funding.
- ☐ Anticipate future service and funding needs.
- ☐ Research eligibility criteria for adult services and funding, application processes and timelines.
- ☐ Gather eligibility documentation (cognitive and adaptive testing, diagnosis).
- ☐ Learn about services and supports for adults by exploring websites, connecting with disability groups and attending events.

Ages 16-21

Actions:

Encourage patient and family to

- ☐ Apply to provincial adult funding and supports as early as possible. Funding and services are often needs based; prepare to highlight key concerns. In Ontario:
- ☐ Developmental Services Ontario (age 16) respite, residential, direct funding, day programs.
- ☐ Ontario Disability Support Program (age 17.5) income support, health and dental benefits.
- ☐ Youth employment programs
- ☐ College programs and educational opportunities (there are programs in Ontario that are accommodating for or specifically designed for people with intellectual disabilities)

Notes

C Transition goals. *Write specific goals with concrete next steps for the patient, family and provider based on your discussion in part A and B. Provide a copy of Part C to the patient and caregivers.*

Patient	Caregiver	Provider
Goal: Next step:	Goal: Next step:	Goal: Next step:
Goal: Next step:	Goal: Next step:	Goal: Next step:
Goal: Next step:	Goal: Next step:	Goal: Next step:

Notes

Next transition planning visit(s):		
Visit 1:	Visit 2:	Visit 3:

Supporting materials

i. **SHARE: Transition Checklist for Youth with IDD and Caregivers**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/general-health/transitions/

ii. **About My Health**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/

iii. **Got Transition [website]**
Center for Health Care Transition Improvement, Washington, DC]
https://www.gottransition.org/

iv. **Healthcare Transfer Plan**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/general-health/transitions/

v. **Transitioning to Adult Care**
Good 2 Go Program [website], Hospital for Sick Children, Toronto
http://www.sickkids.ca/patient-family-resources/resource-navigation-service/transitioning-to-adult-care/index.html

Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up to date.

References

Canadian Association of Paediatric Health Centres (CAPHC), National Transitions Community of Practice. A guideline for transition from paediatric to adult health care for youth with special health care needs: A national approach. Toronto, ON: Canadian Association of Paediatric Health Centres: Knowledge Exchange Network. 2016. Updated June 2016. Accessed 2017 Nov 6.

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This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

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