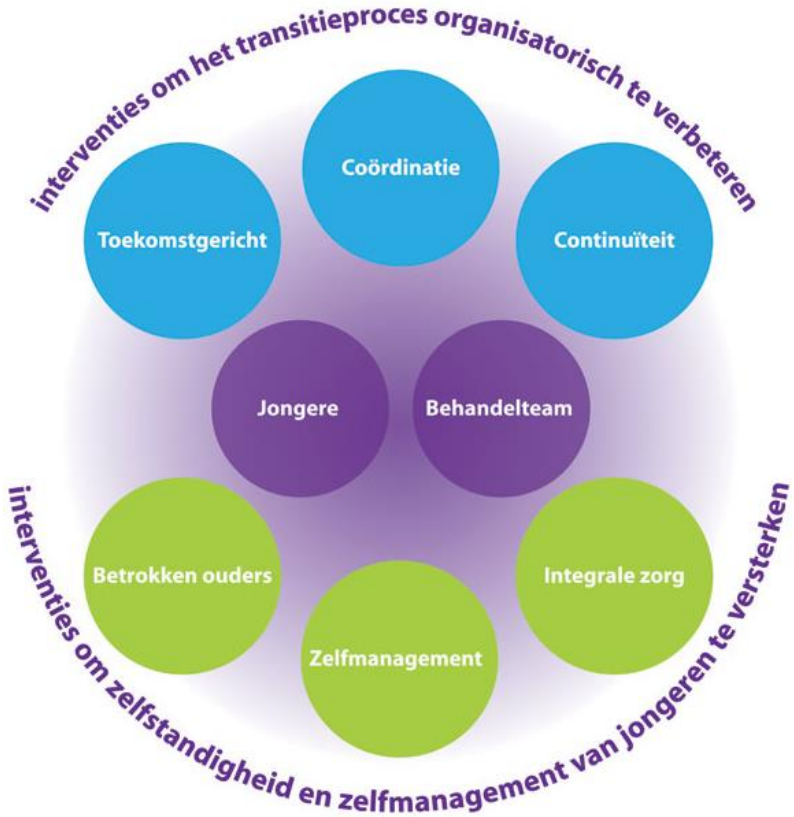
Essentiële elementen in transitiezorg voor jongeren met chronische aandoeningen

Het Op Eigen Benen (OEB) raamwerk is in 2008 opgesteld op basis van de toen beschikbare 'evidence-based' kennis over transitiezorg (Hogeschool Rotterdam & Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008)[1]. Daarbij vormde de review van McDonagh et al. (2006)[2], waarin zij essentiële elementen voor transitiezorg beschrijven, de leidraad. Het OEB raamwerk bevat acht kernprincipes voor goede transitiezorg, onderverdeeld in drie categorieën: 1) interventies die het transitieproces **organisatorisch** verbeteren; 2) interventies om **zelfstandigheid en zelfmanagement** van jongeren te versterken; en 3) de **samenwerking** met jongeren (en hun naasten) en binnen het behandelteam. Het raamwerk is in de praktijk getest binnen het *Actieprogramma Op Eigen Benen Vooruit!* en aangevuld met 'practice-based' kennis. Uiteindelijk vormde het raamwerk de basis voor de Transitie Toolkit (www.opeigenbenen.nu). Dit document heeft doel om het OEB raamwerk te valideren met recente wetenschappelijke kennis vanuit onderzoek en opgestelde richtlijnen.



[1] Hogeschool Rotterdam & Kwaliteitsinstituut voor de Gezondheidszorg CBO. (2008). *Achtergronden bij het raamwerk Actieprogramma Op Eigen Benen Vooruit!* Rotterdam: Hogeschool Rotterdam, Kenniskring Transities in Zorg.
[2] McDonagh, J.E. (2006). Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities. Paper read at Conference 26th March 2006 Department of Health, The Royal Colleges and the Department for Skills and Education.

KERNPRINCIPES 'OP EIGEN BENEN'	*Six core elements of health care transition (Got Transition, 2014; White et al., 2018)*[1]	*Key elements for, and indicators of, a successful transition (Surís & Akré, 2015)*[2]	*NICE guideline on transition (2016)*[3]	*Proposed beneficial features (Colver et al., 2018)*[4]	*Consensus statement on successful transition (Mazur, Dembinski, Schrier, Hadjipanayis & Michaud, 2017)*[5]	*Components of interventions that improve transitions to adult care (Schultz & Smaldone, 2017)*[6]
TOEKOMSTGERICHT	The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through transition processes. The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	Starting planning transition at an early age (and at least 1 year before the transfer boundary). If developmentally appropriate, seeing the adolescent alone at least for part of the consultation.	Ensure a smooth and gradual transition. Collaboration between paediatric and adult care providers. Start early (13 years at latest). Make a transition plan. Meet adult care providers in advance (a transition clinic could help to facilitate this). Provide information about services and support available in adult care.	Meet adult team before transfer: this could be in a joint clinic where pediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician. Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition. Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated.	A structured, written policy involving child and adult healthcare providers. This should be available to adolescents and their family or caregivers. Starting to create a healthcare transition plan as early as possible, for example by the age of 14 or below or at least one year before the transfer itself. The transition process and timing should be individualized.	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group.
COÖRDINATIE		Assuring a good coordination (such as timing of transfer, communication, follow-up,	Appoint a named worker to coordinate the transition care and support.	Key worker: a single person known to the young person whom they could easily contact or go		A transition coordinator may be helpful in optimizing clinic attendance. They could

		remaining available as a consultant, etc.) between pediatric and adult professionals.		to if there were any problems of co-ordination or misunderstandings that needed to be sorted out. Transition manager for clinical team who facilitates good working relationships between adult and child services; ensures that there are appropriate materials available for things such as health education or the transition plan; and monitors whether the young person has a suitable appointment in adult services and whether the appointment is kept.		provide assistance with scheduling appointments and following up if appointments were not attended.
CONTINUÏTEIT	The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff. The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals / actions, medical summary and emergency care plan, and, if needed, legal documents, and a	Identifying an adult provider willing to take on the young patient before transfer. Patient not lost to follow-up.	Ensure a smooth and gradual transition. Collaboration between paediatric and adult care providers.	Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team.	A structured, written policy, involving child and adult healthcare providers. Continuity of care and cooperation, i.e. using common medical guidelines, keeping proper medical records, and performing follow-up evaluations. Continuity of financing.	

	condition fact sheet), and pediatric clinicians communicate with adult clinicians, confirming pediatric provider's responsibility for care until young adult is seen in the adult practice. The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.					
JONGERE	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	Including young person's views and preferences to the planning of transition.	Involve young people and their caregivers in service design, delivery and evaluation of transition care. Transition support must be developmentally appropriate. Transition support must be strengths-based.		Procedures should be available to adolescents and their family or caregivers, and should allow for some flexibility, depending on the adolescent's developmental stage as well as the expectations and needs of the patient and relatives. Active participation of the adolescents and the parents or caregivers should be sought. The transition process and timing should be individualized.	
BEHANDELTEAM	The practice has incorporated transition into its plan of care. All clinicians are encouraged to partner with youth and families in developing transition goals and		Collaboration between paediatric and adult care providers. Meet adult care providers in advance (a transition clinic could help to facilitate this).	Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team. Meet adult team before transfer: this could be in a joint clinic where	Adequate staff training and sensitization to the needs and concerns of adolescent patients. Interdisciplinary teams.	

	updating and sharing the plan of care. Clinicians are also encouraged to address needs for decision-making supports. The practice has a vetted list of adult providers and assists youth in identifying adult providers.			pediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician. Coordinated team of which the members need to work together and communicate well together, and demonstrate to the young person that this is happening. Coordination of appointments on the same day demonstrates this.		
BETROKKEN OUDERS	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	Discussing with patient and family about self-management.	Involve young people and their caregivers in service design, delivery and evaluation of transition care.	Appropriate parent involvement in their child's care, but with changing responsibilities. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and also discussions at home about the young person's health and how to manage it.	Active participation of the adolescents and the parents or caregivers should be sought.	
ZELFMANAGEMENT	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs and goals are incorporated into the youth's plan of	Discussing with patient and family about self-management. If developmentally appropriate, seeing the adolescent alone at least for part of the consultation.		Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition and the young person is asked *"Have you received enough help to*	The extent to which the adolescent has acquired some skills for self-management should be taken into account.	Psychological support may help youth learn how to balance their multiple priorities as well as cope with challenges such as understanding how their illness affects their self-image and avoiding becoming isolated from their social circles.

	care beginning at ages 14 to 16.			*increase your confidence in managing your condition?"* Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.		
INTEGRALE ZORG		Although having a holistic approach to prepare young people for adulthood was not unanimously considered as essential or very important, it is an important part of transition. In fact, it seems that the consensual elements in the study of Surís and Akré (2015) are mainly limited to health outcomes.	Using a person-centered (holistic) approach. Involve primary care (general practitioner).	Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated. Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.	Young patients should not be transferred until they have the skills to function in an adult service and have finished growth and puberty. The extent to which the adolescent has acquired some skills for self-management should also be taken into account, as well as their own expectations. Adolescent patients with chronic conditions have specific needs that go far beyond treating their condition. These concerns are usually better addressed by an interdisciplinary team.	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group including taking responsibility for their diabetes, experimenting with drugs or alcohol and managing diabetes away from home. Transition clinics can also give adolescents / young adults an opportunity to meet with providers of different disciplines.

[1] Got Transition (2014). *The Six Core Elements of Health Care Transition (2.0).* Geraadpleegd van http://www.gottransition.org // White, P.H., Cooley, W.C., Transitions Clinical Report Authoring Group, AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AMERICAN COLLEGE OF PHYSICIANS. (2018). Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*, 142 (5): e2018258.

[2] Surís, J. C. & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56(6),* 612–618.

[3] National Institute for Health and Care Excellence. (2016). *NICE guideline: Transtion from children's to adults' services for young people using health or social care services.* Geraadpleegd van nice.org.uk/guidance/ng43.

[4] Colver, A., Pearse, R., Watson, R.M., Fay, M., Rapley, T., Mann, K.D., Le Couteur, A., Parr, J.R., McConachie, H., Transition Collaborative Group. (2018). How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Services Research,* 18: 337.

[5] Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Pædiatrica, 106,* 1354–1357.

[6] Schultz, A. T., & Smaldone, A. (2017). Components of interventions that improve transitions to adult care for adolescents with Type 1 Diabetes. *Journal of Adolescent Health, 60,* 133-146.

CONCLUSIE

ORGANISATIE VAN HET TRANSITIEPROCES

- **TOEKOMSTGERICHT:** Een schriftelijk protocol of beleid helpt om de transitie toekomstgericht en planmatig vorm te geven. Tijdig beginnen met de voorbereiding (rond het 14e levensjaar) en stapsgewijs toewerken naar meer verantwoordelijkheid en zelfstandigheid voor de jongere zijn belangrijke elementen hierbij, evenals kennismaken met de nieuwe zorgverleners voorafgaand aan de overstap.

- **COÖRDINATIE:** Het aanstellen van een transitiecoördinator die het proces bewaakt (incl. de communicatie en afstemming tussen zorgverleners van de kinder- en volwassenenzorg; en de logistiek rondom de transitie en transfer), en die daarnaast het aanspreekpunt vormt voor jongeren en hun ouders, wordt aanbevolen.

- **CONTINUÏTEIT:** Een gezamenlijk transitiebeleid, goede overdracht van informatie (zowel mondeling als schriftelijk) waarbij men in de kinderzorg weet naar wie de jongere wordt overgedragen, en het monitoren en evalueren van follow up dragen bij aan continuïteit van zorg in de transitiefase. Ook een passende financieringsvorm is belangrijk.

SAMENWERKING TUSSEN JONGERE EN BEHANDELTEAM

- **JONGERE:** Transitie is maatwerk en moet worden aangepast op de individuele situatie/ontwikkeling van de jongere. Daarbij moeten de jongeren actief worden betrokken bij de zorg. Hun wensen, behoeften en voorkeuren moeten worden achterhaald en serieus genomen. *"Luister naar de stem van de jongere,"* is de boodschap.

- **BEHANDELTEAM:** Interdisciplinaire afstemming en samenwerking tussen zorgverleners uit de kinder- en volwassenenzorg, afstemming van werkwijzen en procedures (waar mogelijk en relevant), kennismaking met nieuwe zorgverleners voorafgaand aan de transfer zijn essentiële elementen voor goede transitiezorg.

VOORBEREIDING OP ZELFMANAGEMENT EN ZELFSTANDIGHEID

- **BETROKKEN OUDERS:** Ouders moeten betrokken worden in de zorg rondom de transitie van hun kind en moeten begeleiding krijgen bij het geleidelijk overdragen van regie en verantwoordelijkheden aan hun kind.

- **ZELFMANAGEMENT:** Een persoonsgerichte en holistische benadering is belangrijk om jongeren optimaal te ondersteunen in hun transitie. Er moet niet alleen aandacht zijn voor transitie in medische zin, maar ook voor psychosociale ontwikkelingen en uitdagingen waarmee jongeren in deze levensfase te maken hebben. Jongeren moeten in brede zin worden voorbereid op zelfstandigheid en zelfmanagement. Hierbij is *developmentally appropriate care* om te werken aan zelfeffectiviteit en om een optimale *readiness for transfer* te bereiken van groot belang.

- **INTEGRALE ZORG:** Jongeren in de transitiefase hebben te maken met allerlei uitdagingen en daarom is een persoonsgerichte en holistische benadering belangrijk. Dat betekent aandacht voor het bereiken van optimale participatiedoelen voor een optimale volwassenwording. Indien nodig, kunnen jongeren door hun vaste behandelaars worden doorverwezen naar de juiste professionals (zoals een psycholoog, maatschappelijk werker of diëtist).

TOT SLOT

Alle elementen van het OEB raamwerk zijn terug te vinden in de recente reviews, richtlijnen en indicatoren. Daarmee biedt het raamwerk concrete handvaten voor de beschrijving, inrichting en beoordeling van transitiezorg binnen een instelling of organisatie. Om deze elementen te realiseren is echter niet alleen inspanning van de zorgprofessionals binnen een organisatie noodzakelijk. Er moeten ook randvoorwaarden worden gerealiseerd die transitiezorg faciliteren, ondersteunen en mogelijk maken. Deze gedachte sluit aan bij het Chronic Care Model[3], het Generiek model Zelfmanagement[4], en het Tien punten programma Betere Transitie in Zorg[5].

Randvoorwaarden zijn bijvoorbeeld:

- **Wet- en regelgeving**: nationaal en/of internationaal.
- **Kwaliteitseisen**: beschikbaarheid van een nationale kwaliteitsstandaard voor transitiezorg en/of ontwikkeling van kwaliteitsnormen waaraan moet worden voldaan.
- **ICT faciliteiten**: een gezamenlijk elektronisch patiëntendossier dat uitwisseling van gegevens en continuïteit van zorg faciliteert.
- **Opleiding en scholing**: aandacht voor adolescentengeneeskunde, transitie in zorg en ontwikkelingsgerichte zorg.
- **Management**: bieden van positieve ondersteuning en ruimte voor innovatie en onderzoek.
- **Financiering**: zorgen voor financieren van gezamenlijke zorg inspanningen, extra aandacht voor voorbereiding/ begeleiding.

[3] Bodenheimer, T., Wagner, E., & Grumbach, K. (2002). Improving primary care for patients with chronic illness: the chronic care model. *JAMA, 288,* 1775-1779.
[4] Kwaliteitsinstituut voor de Gezondheidszorg CBO. (2014). *Zorgmodule Zelfmanagement 1.0.* Utrecht: CBO.
[5] Opgesteld tijdens de Ronde Tafel die in oktober 2017 georganiseerd werd door FNO.