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Pessac-Bordeaux



Handicap de l'enfant et précarité psycho-socio-économique :

spécificités, écueils , enjeux

Une préoccupation partagée?

Social prescribing: can it help disabled children?

Day-to-day clinical practice in child neurology provides frequent reminders that despite our best efforts, medical management represents only a small fraction of the determinants of health. Genetic factors, social circumstances, environmental conditions, and behavioural choices together have a greater effect on health outcomes than medical management.¹ Inequalities exist in all of the above: with a few notable exceptions to date, genetic factors can not be addressed, but the others can, should be, but often are not.

It is worth taking a moment to reflect on non-medical influences on health facing children with complex chronic conditions and their families. Families spend many hours providing and coordinating care, often experiencing new financial pressures as they cut back or cease their paid working hours to accommodate this role.² For some, this will be the tipping point into poverty, with further adverse effects on health. Furthermore, families with a child with a chronic complex condition often have multiple unmet non-medical needs and express difficulty accessing community services.² The COVID-19 pandemic has heightened these pre-existing problems through increasing social isolation, adversely affecting mental health and disrupting service provision,^{3,4} as documented by the Disabled Childrens Partnership in their 2020 report 'Left in Lockdown' (<https://disabledchildrenspartnership.org.uk/left-in-lockdown/>).

I strongly believe that all practitioners have a responsibility towards addressing the broader determinants of health of their patients – but we do not have the resources to do this all on our own. By its very definition, unmet need is not being adequately addressed by existing services. In primary care, the proposed solution is 'social prescribing'.⁵ This term is perhaps confusing as it suggests a formulaic approach in which a specific service is prescribed to address a specific condition. However, the approach is necessarily more flexible than its pharmacological namesake: social prescribing relies on matching locally available community assets to the needs and interests of the client. In practice, this matching process is done by a link worker, following voluntary referral to the service. The link worker takes time to discuss the clients' priorities and supports

them in engaging with appropriate local services.

Social prescribing is a key component of universal personalized care, supported through NHS England as part of the NHS Long Term Plan. At present it is mostly accessed by adults. There is emerging evidence of improved well-being, as discussed in a recent report by the Kings Fund. Schemes for young people are emerging, but to date there is only one reported evaluation, accessible through the University of East London repository (<https://repository.uel.ac.uk/item/88x15>). Findings are preliminary but encouraging.

Community-based social prescribing schemes for a younger demographic are also surfacing; however, the adult model of supporting non-medical needs of those with complex chronic medical conditions has yet to be applied fully to children, and would require adaptation. A more family-centred approach would be necessary, partly for the family to help the link worker understand the child's needs and partly to address related family needs. Potential tensions between competing interests amongst family members could arise and would have to be managed. Link workers would likely benefit from specific training in working with children with additional needs and would require support and mentoring. Gaps in community provision for children with disability will undoubtedly be highlighted, but identification is a necessary first step to filling those gaps. In short, we must ensure that children with disability and their families are not overlooked in the roll-out of social prescribing services, and we must evaluate the benefit of the approach.

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2. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med* 2011; 165: 1020–6.
3. Queen Mathile HM. Parents of children with disabilities and the COVID-19 pandemic. *Dev Med Child Neurol* 2021; 63: 1009.
4. Schiariti V. The human rights of children with disabilities during health emergencies: the challenge of COVID-19. *Dev Med Child Neurol* 2020; 62: 661.
5. Drinkwater C, Wildman J, Moffatt S. Social prescribing. *BMJ* 2019; 364: 11285.

Le sujet?



Handicap de l'enfant : tous handicaps confondus (pour les données statistiques);
handicap physique, polyhandicap (REHSO)

Précarité : santé mentale et physique, équilibre familial, professionnel, financier
(question migratoire exclue)

Les constats :

Une Multiplicité d' acteurs concernés:

- Action médicale :

Médecine de ville, Santé scolaire, hôpital, SSR

- Action médicosociale : ESMS, PCPE, CAMSP, PMI...

- Action départementale : MDSI, ASE : les mesures administratives (AED, TESF, AESF, Placements), MDPH.

 - _ ARS

- Action judiciaire : AEMO, placements

Et ... beaucoup d'autres dispositifs!!

Des difficultés à établir des données statistiques

Un morcellement et cloisonnement des parcours

Quelques chiffres...

Rapport du défenseur des droits (2015) : « Des droits pour les enfants invisibles »

- 70000 mineurs relevant de l'ASE sont en situation de handicap.
- Enquête portant sur 43 départements : 13 à 25% des jeunes relevant de l'ASE sont en situation de handicap
- Notification MDPH : 17% des enfants relevant de l'ASE contre 2 à 4% dans la population.
 - La moitié : AEMO ou AED
 - La moitié : placement judiciaire ou administratif
- Prédominance de troubles psycho-comportementaux

• Rapport ODPE Gironde 2020 :

- 16% de notifications MDPH dans la population relevant de l'ASE
- Prédominance de difficultés intellectuelles et psychiques

Que veulent dire ces chiffres?

- **« Handicap : porte d'entrée dans l'ASE »**

Le handicap de l'enfant fragilise la famille

(*enquête DREES novembre 2020*)

Parents d'enfants handicapés :

- <30% des pères ou mères sont diplômés de l'enseignement supérieur
 - 53% des deux parents en couple travaillent (-17%/ Pop générale)
 - Famille monoparentales (17% dans pop générale) : 30% des bénéficiaires de l'AEEH
- Isolement.....Séparations....

- **La précarité favorise le handicap**
(*« Faire Face ». Octobre 2020*)

- Handicap psychique
- Handicap physique (prématurité, accidents)

- **La précarité pousse à la reconnaissance MDPH**
- **La précarité est un facteur de surhandicap**

Diversité et complexité des situations



Quelques exemples cliniques

Le point de vue de l'assistante sociale

Enfants relevant de l'ASE :

Liens FA , Foyers, milieu sanitaire et médicosocial

PCH; aides matérielles , aménagement domicile, aides humaines

Enfants ne relevant pas de l'ASE

Finances, logement, complexité administrative, continuité des soins, scolarité, autres membres de la fratrie

La transition enfant-adulte

Prendre un peu de recul

La compétence parentale : comment la faire émerger

Les ressources Institutionnelles

Le **dépistage** précoce : PMI et premières orientations : CAMSP, CMPP, CMPEA

Les **diagnostics partagés** : liens ASE-MDPH : situations complexes